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ABSTRACT

This proceedings contains presentations grouped by five broad topics concerning disability services in rural areas. The keynote address, by Linda Tonsing-Gonzales, discusses the social services paradigm shift toward empowering the disabled and developing natural support systems. Broad topics and presentation topics are: (1) "negotiating access" (rural independent living centers, the Americans with Disabilities Act, consumer-driven community service networks and supportive housing, home accessibility, and alternative funding strategies); (2) "networking partnerships" (rural resource networks, early intervention, independent living for older people with visual disabilities, and interagency networking); (3) "training resourcefully" (preservice teacher education, an experimental program meeting special educational needs of disabled secondary students in the regular classroom, training master trainers for staff, and a school-based health promotion program); (4) "cultivating careers" (rural issues in rehabilitation, providing integrated employment services, and activism and leadership development among disabled persons); and (5) "weaving natural supports" (church-sponsored supportive home groups, integrating disabled children into community recreation programs, and a community-based independent living center). Informal forum topics include Native Americans and disability issues, rural supported employment, rural mental health, and identifying effective rural programs and strategies. This document lists rural information resources, program participants, and related state agencies. (SV)

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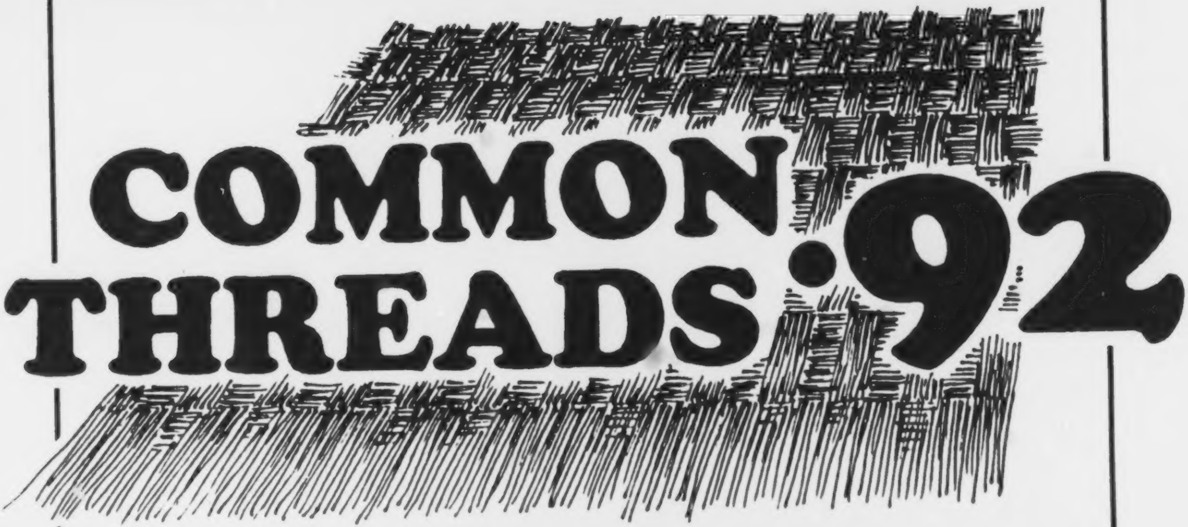
Weaving Together Rural Resources for People with Disabilities

COMMON THREADS '92



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PROCEEDINGS

Common Threads Conference
August 22-24, 1992
Missoula, Montana

Montana University Affiliated Rural Institute on Disabilities

The University of Montana, Missoula, Montana

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COMMON THREADS

Weaving Together Rural Resources for People with Disabilities

Proceedings of the 1992 Common Threads Conference

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Sponsored by the
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Montana University Affiliated
RURAL INSTITUTE ON DISABILITIES

The Montana University Affiliated Rural Institute on Disabilities (Rural Institute) is an interdisciplinary, university-sponsored organization that promotes the full participation in rural life of individuals of all ages with disabilities by developing and disseminating innovations in teaching, research, community services and policy advocacy.

In 1978, the federal Administration on Developmental Disabilities (ADD) acknowledged the need for a University Affiliated Program in Montana. ADD granted funding and the Rural Institute began operation on the University of Montana campus in 1979. The Research and Training Center on Rural Rehabilitation Services (RTC:Rural) was established within the Rural Institute in 1987, with funds from the U.S. Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). Throughout its history, the Rural Institute has clarified its mission, steadily increased the number of its programs and expanded the scope of its activities to a national scale.

The Rural Institute conducts service, training, technical assistance, research and information dissemination activities which:

- help people with disabilities in rural areas access **quality social and educational services and health care,**
- increase the quantity and quality of **disability service professionals and providers in rural settings,**
- discover and develop **state-of-the-art approaches** to meet the challenges of living with a disability in rural areas, and
- provide **information about rural issues** to the public and professionals.

The ultimate aim of the Rural Institute on Disabilities is to improve the independence, productivity and community integration of rural Americans with disabilities.

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INTRODUCTION

On August 21-24, 1992, the Montana University Affiliated Rural Institute on Disabilities sponsored the conference **"Common Threads '92: Weaving Together Rural Resources for People with Disabilities"** in Missoula, Montana. The goals were to bring together people knowledgeable about disability services in rural areas and to help them share their experiences, challenges and solutions: their "common threads."

Speakers made presentations on exemplary programs in five topic areas:

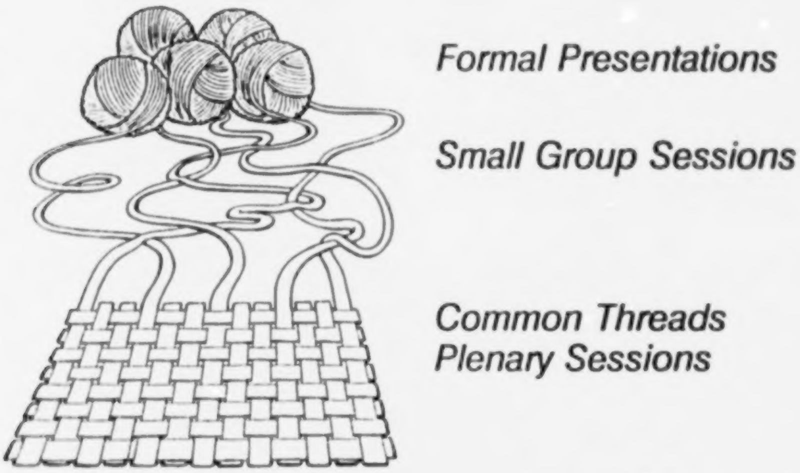
Negotiating Access
Networking Partnerships
Training Resourcefully
Cultivating Careers
Weaving Natural Supports

After the presentations in each topic area, conference participants adjourned to small group sessions, where facilitators guided the discussion to highlight the ways that participants' programs had responded to the challenge of the topic area. Participants were encouraged to share experiences, expertise, and problems. The facilitators kept notes on flipcharts, then distilled each one-hour discussion into a single sheet of "common threads."

Each participant was also provided with a "do-it-yourself conference participant's resource directory." As the participant rotated through various small group sessions, she or he could enter information on this form in a space next to each participant's name: detailing areas of expertise, type of program, innovative techniques, etc. This helped participants get to know each other better and encouraged networking.

The groups reassembled for morning and afternoon Common Threads plenary sessions, in which all the facilitators summarized the small groups' contributions -- followed by a general discussion of the topic area by the entire group. The diagram below illustrates the overall flow of the conference from the initial presentations, through the small group discussions, to the plenary sessions.

Programmatic Flow
(a playful representation)



This document contains the papers of the presenters' talks, grouped by topic area and followed by the "common threads" for each area: summaries of the comments made during each plenary session. Comments are grouped according to subject matter, but not in order of mention or importance. They are all equally important, although "common threads" that were voiced the most frequently are printed in boldface type. These Common Threads plenary sessions elicited positive, proactive statements comprising the collective wisdom of some very innovative rural disability programs, and we are pleased to be able to share that wisdom with you.

KEYNOTE

NATURAL SUPPORTS AND THE PARADIGM SHIFT

Linda Tonsing-Gonzales, Director
New Vistas Independent Living Center

"Interdependence, as with life, is about we. Indeed, an enriched life is about connections. ... In a broader sense, it is about community." - Al Condeluci

Natural Supports in the Midst of Shifting Paradigm

The subject of Natural Supports is not a new one. In fact, it is the culmination of a cycle and a return to the beginning of valuing the individual. It is an evolution from the current view of the professional/bureaucratic model of dealing with people with disabilities, to a changing paradigm which has the individual at the center and locus of control. It has grown out of a necessity to meet the inadequacies of big business rehabilitation that too often spews people back into their community with nothing tangible to transfer and no money left for support.

The implications for developing natural supports goes far beyond creatively organizing "1000 points of light." If indeed we are looking at a paradigm shift toward having the individual in control, we are likely to encounter growing resistance and rigidity. In an excellent excursion into the realms of conceptual revolutions, David B. Schwartz writes compellingly in his book, Crossing the River Creating a Conceptual Revolution in the Community and Disability (1992). In speaking of the community services programs that grew out of the deinstitutionalization movement, he states, "Abuse, neglect, drugging, discontinuity of relationships, pervasive isolation, the reduction of people to aggregations of clinical syndromes, feelings by those served that they are being retarded by services: these are serious indictments indeed of a service system founded to free people from abuse and to promote growth and freedom" (p. 71).

Three visions of society underlie social action on behalf of labeled people, according to Schwartz: 1) the therapeutic vision that sees well-being derived from having an environment of professionals and their services; 2) the advocacy vision that is the world guarded by legal advocates, support people, self-help groups, job developers ... "a defense wall of helpers to protect against an alien community" (McKnight, 1987). This second vision may well be where many independent living activists find themselves. So adamant to become an integrated part of community, IL leaders spend considerable time and energy in activities of systems advocacy. Schwartz cautions that this second vision is still not the solution to repairing a crumbling system. "Systems advocacy," he rightfully points out, no matter how forceful the advocacy, "can only advocate for systems" (p. 117). The third vision, the "community vision," is the basic context in which people are enabled to contribute their gifts.

In another article examining the crisis for disenfranchised groups in urban cities, including people with disabilities, Stephen Hays holds out a hope for a return to a simple rural life as the only solution to homelessness, unemployment and a hopeless future. Fascinated by time spent in a small village in the Greek islands where every resident of the village was a functioning, contributing member, Hays would like to see this model available to the expanding class of have-nots in America. "The welfare system seems like pouring money down the drain because it is: we do not give money to the poor, but only through them...Our welfare money goes through the poor to somebody" (Hays, 1992).

In the case of people with disabilities, the billions of dollars purported to be spent on them annually flow through them to private rehabilitation facilities, vocational programs, the nursing home industry, home health care, landlords, grocery stores and retail stores. The individual person is no better off economically, and indeed in the age of high inflation and rising taxes is losing ground financially. Add to this the fact that 75 percent of people with disabilities are unemployed or under-employed, and you have a system that must be changed in order to survive.

The Role of Independent Living Centers

The independent living movement, the soul of consumerism, needs to find a way into the vast unserved rural areas of America. We need to clarify who we are and what we do. Throughout the years of my association with the independent living movement, I have had to repeatedly state two somewhat opposing facts about my chosen field. First, I have had to explain that the independent living center is not a residential facility where people with disabilities move in and live. At the same time, I've had to reiterate that independent living does not mean living alone. These statements viewed together are not contradictory, but they do seem a little confusing.

Traditional residential programs, such as group homes, smack of segregation to the hard-line independent living advocate. Yet if two, three or four people with disabilities get together and decide to pool their resources and share a living space and perhaps an attendant, that arrangement is perfectly acceptable. The issue is not necessarily group living so much as how the living arrangements are determined.

Typically, those folks living in a group home have a cadre of professional and/or semi-professional workers revolving around them. They are subjected to lengthy house rules and regulations imposed by licensing facilities. They are likely to be supervised on an around-the-clock basis, whether they need that level of assistance or not. More often than not, they are chauffeured to jobs, work centers, day care or doctors' appointments. At any given moment in time, one would likely find their beds made, their dishes clean, their floors swept. They, more likely than not, had nothing to do with selecting the people with whom they share their very lives (roommates or workers).

In a nutshell, they have little or no control in making the critical choices others take for granted without a second thought. That is the crux of independent living -- choice and control. As much as those in positions of power and professionalism may hate to hear it, independent living advocates do believe that the person with the disability knows best what he or she needs and wants. The goal of empowerment to the person pervades every disability type and group.

It is an idea whose time has come, regardless of the significant impact it will have on professionalism and big business. Unless everyone understands this and modifies their work approach accordingly, they will find themselves in an obsolete career. Providers need no longer see themselves as working for people with disabilities but rather working with them to create interdependent relationships whether they be paid services or natural supports. "You can get anything you want in life, if you just help enough other people get what they want" (Zig Ziglar).

Service Providers and the Paradigm Shift

How can we, as professionals who may see the shifting paradigm that has been hovering around us as the independent living/disability rights movement, best respond to the inevitable? We've already made considerable concessions to the concept of "consumerism." How else can we "lead, follow or get out of the way?" Perhaps our role is to become better facilitators, services coordinators and advocates to the people we serve. The only "managing" left to be done is how to manage to keep the bureaucratic quagmire of rules, regulations, eligibility, etc. minimized so that the community services movement doesn't follow the same course as the institutional era.

The real systems advocacy that we must concentrate on is to insist that state and federal laws streamline and unify their efforts to make services available as simply and quickly as possible without creating dependency on that system. We must advocate to insurance companies and to the health care industry to establish service funding to follow the consumer back into the community. "Without the human community, one single human being cannot survive" (H.H. the Dalai Lama).

Implementing a Natural Support System

Developing a system of natural supports for people with disabilities involves minimizing or eliminating the professionals and maximizing the relationships that occur naturally. The purpose of natural supports must go beyond "consumer needs" to enhance consumer contributions to the community. True, independence is interdependence. The natural supports will evolve as we begin to listen to the consumer. Some will need help identifying these relationships; others will not.

New models are being introduced to address the need to integrate people with disabilities into the community's social network. One approach, the Circle of Friends, begins to address the issue by formally identifying people who might be potentially helpful to the individual with a disability. The Circle, which may include family members, professionals or friends, comes together to help that person pursue and realize an identified goal or dream (chosen by the person). That person, while admittedly in control of the process, can dismiss the group when it is no longer needed (Community Integration, February 1992).

Such a model would be enhanced if it focused more on an interdependence exchange instead of a dependent "you help me get what I want" approach. Other model projects have been funded in Pennsylvania to encourage the development of interdependent social networks for people with developmental disabilities. The funded projects had remarkable success pairing people with disabilities to people of diverse backgrounds from the community. The relationships, which developed interdependently, not only created social networking for the individual, but also provided them with a means to contribute their uniqueness and talents to the community (Schwartz, 1992). Whether through giving scriptural readings at the local church, collecting vouchers at a food bank or a single paraplegic woman adopting a daughter, true integration had occurred through interdependence.

Community Action Groups that come together to address disability and/or community issues can also be a source for nurturing natural supports. Instead of just identifying care supports (drivers, attendants, job coaches), it is important to foster social relationships as well.

Conclusion

Empowering the individual is at the heart of the paradigm shift. Finding the heart of community through interdependence of both natural supports and paid services that foster total integration, participation and contribution: That is the task before us. It is not an easy one, but it is the only ethical solution.

For more information contact Linda Tonsing-Gonzales, New Vistas Independent Living Center, 2025 S. Pacheco, Suite 105, Santa Fe, New Mexico 87505; 505/471-1001.

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NEGOTIATING ACCESS

Access determines your lifestyle, the landmarks and the boundaries of your personal and social environment. Access has many aspects, and is much broader than curb cuts and usable toilets. It is vital to remember that access includes: physical access, economic access, communication access, attitudinal access, cultural access, transportation access, educational access, career access, etc. Removing only physical barriers will not result in integration, mainstreaming, inclusion, or whatever words you use to understand these issues.

Accessibility is a community issue. Access is the essence of full integration and community participation. With the passage of the Americans with Disabilities Act, accessibility is now a civil rights issue. What were previously "special needs", are now generic access issues. This civil rights protection, like each child's right to a free and appropriate public education, allows people to redefine their relationship to the community. When people have the right to access education, to access the telephone system, to access restaurants in the community, it doesn't take long to realize that when the environment is less hostile, a disability isn't a handicap.

The 1991 Concise Oxford Dictionary defines "access" as:

1. a way of approaching or reaching or entering.
2a. right or opportunity to reach or use or visit; admittance.
2b. the condition of being readily approached; accessibility.

and "accessible" as:

1. that can readily be reached, entered, or used.
2. readily available.
3. easy to understand.

and "negotiate" as:

1. confer with others in order to reach a compromise or agreement.
2. arrange (an affair) or bring about (a result) by negotiating.
3. find a way over, through, etc. (an obstacle, difficulty, fence, etc.).
4. transfer to another for a consideration.

Common Threads '92 includes both nuances of **NEGOTIATING ACCESS:**

1. figuring out satisfactory ways to enter and use the community as a whole.
2. bargaining with others to develop the means of entry and integration.

RURAL INDEPENDENT LIVING CENTERS EXEMPLARY PRACTICES

Earl Walden, Program Associate (Presenter)
Research and Training Center on Indepenedent Living

More than 8.5 million people with disabilities live in rural or non-metropolitan areas. The 12.7 percent of rural Americans who have disabilities exceeds the 10 percent of the urban population who are disabled. The barriers to independent living are inversely proportional, with the greater percentage of people with disabilities in a rural setting facing more barriers to independent living than their urban counterparts. Based on the above inequities, a project has been developed to help rural independent living centers meet some of the needs.

Independent Living Research Utilization (ILRU), a national center for information, training, research and technical assistance for independent living, is involved in this project to identify and document exemplary practices in community based independent living service delivery to persons with disabilities who live in rural areas and to disseminate information on those practices that warrant replication in other rural areas.

The first task of this project involved the identification of community based centers that are engaged in the delivery of independent living and supportive services to people with disabilities who live in rural areas. A project advisory committee has been convened to assist in developing criteria for judging exemplary practices. Applications were received from centers with prospective exemplary practices in each of the priority areas. Centers judged to be exemplary by the advisory committee will be included in the technical assistance network on exemplary practices in rural community based service delivery. Centers identified as exemplary will be invited to contribute materials for ILRU's Resource Materials Directory.

Six demonstration sites representing different rural demographies will be selected across the nation. Using the technical assistance network and supporting materials developed by the ILRU project staff, intensive support services will be provided at the demonstration sites. The final step of the project will be to disseminate to the field the results of the project and to make available rural-focused technical assistance services and supporting materials developed during the project.

The priority areas were identified using a two-round Delphi survey of rural independent living directors. The five most critical issues of rural independent living service delivery are:

- transportation and distance barriers;
- innovative, supplemental funding sources and methods;
- affordable, accessible housing;
- barriers to accessibility; and
- attitudinal barriers.

The leading priority of rural independent living center directors was the barrier of distance and transportation. Rural areas are primarily void of organized public transportation systems, and the private systems that are available are mostly inaccessible. Two exemplary awards were granted in the transportation division of this project; one was LINK Inc. of Hayes, Kan., and the other was New Vistas of Santa Fe, N.M.

Ellis County, Kan., the site of the city of Hayes, had no public transportation, not even a taxi. Several service organizations had lift vans, but service was limited and restricted to a specific group. As a result, the needs of Ellis County citizens were not being met, and none of the transportation services were cost effective. Pressure by the state funding agency prompted the five agencies to meet and establish the largest agency as the operator/administrator with LINK developing the guidelines and schedules, and setting up an advisory council. LINK also educated the cooperating agencies about the need for accessible transportation that could be responsive to consumer requests. After the successful co-op was formed, the administrative agency and LINK generated additional funds from the county and city to expand the service. Last year the service averaged more than 2,000 rides per month; the most recent monthly figures show utilization by 2,883 riders.

New Vistas Independent Living Center in Santa Fe, N.M., was awarded a grant by the state to establish a program in Raton, a community of about 8,000 people in Northern New Mexico, for the purpose of providing employment services. One of the major barriers to employment for people with disabilities in the area was accessible transportation. The area was canvassed to find an organization to share a partnership for a lift van. A local church, which needed a van for Sunday services transportation, agreed to provide drivers and insurance. Together, the church and New Vistas wrote a grant request to the Urban Mass Transit Authority and raised local matching funds of approximately $5,000. With the support of the van, 40 people with disabilities have found employment. The van also serves community members with disabilities as they travel for medical and health services, shopping, social and recreational trips. The van is used by the church for their outreach ministry and has served the Girl and Boy Scouts, Special Olympians, 4-H clubs and nursing homes.

The award for an exemplary funding practice was given to the Resources Center for Independent Living Inc. of Osage City, Kansas. The practice was germinated by a request from a consumer with deteriorating eyesight. This person could not drive, had a family in another state and preferred not to move to a nursing home during the harsh winter months. Many of RCIL's consumers were in this situation: During most of the year their families could visit periodically and perform emergency chores, but during the winter months these visits were impractical, so the consumers, acting of necessity and contrary to their personal and philosophical desires, moved into a nursing home or with other relatives. RCIL built on a "call-check" program used for telephone consumers during the winter months: Start-up funds were obtained by donations from local organizations, and volunteers organized to provide the program manpower.

A referral initiates a visit to determine the need and the acceptance of assistance. Volunteers are assigned to perform the necessary tasks. Funds are replenished through donations at the hardware stores, which credit the contributions to the account used to purchase materials necessary to fulfill the consumers' needs. Shopping for these homebound consumers is also done by volunteers, with home delivery by the same or other volunteers. The grocery stores contribute to the program by itemizing the bills and mailing them to participants' homes. Consumers are called on a daily basis, and if there is no response, the police are called to check on the home. This two-year-old program served 30 people during the past year and exists on a small budget, most of it from donations.

The primary barrier facing people with disabilities is attitudinal -- attitudes of self, family, school, community, employers, providers and anyone who sees a person with a disability as someone "different." ILRU awarded two centers for their work in attitudinal projects: North Central Center for Independent Living in Lewisburg, Pa., and the Illinois-Iowa Center for Independent Living in Rock Island, Ill.

The North Central Center for Independent Living (NCCIL) was awarded a grant from the Pennsylvania Developmental Disabilities Planning Council for a parental support group. The group formed using the name PATHS. The first meetings uncovered the great concerns of these parents: mainstreaming without support services; classes aimed at mental retardation; and light effort for integration. Pennsylvania was in the process of implementing new guidelines for special education, and as always rural schools were underfunded, understaffed, and untrained. The Education Law Center educated the participants of PATHS about their children's educational rights, and the group was empowered to assume an active advocacy role for their children. Children with hidden disabilities were not being accommodated; they were receiving failing grades, behavioral discipline and classification as "uncooperative juvenile delinquents."

The PATHS project coordinator, with the advice of the group, determined that the initial approach should be an "Educate the Educators" project. Working with one family reviewing their child's educational rights and developing an educational strategy plan, the parents and the coordinator met with school personnel. The meeting was stressful, but the school personnel were able to admit that the educational process was not working for many children with severe disabilities and that PATHS and NCCIL could provide information to the school that would benefit the educational system in regard to the impact a disability makes on learning processes. Although all is not paradise, school personnel have started attending PATHS meetings, and PATHS and NCCIL are invited to the in-services and workshops. Parents have educated themselves to be a part of their child's educational future, and school personnel have learned about meeting the needs of children with special needs.

The Illinois-Iowa Independent Living Center developed and implemented a plan to reach unserved minorities in a rural Midwestern community. The project was ambitious: Minorities included African Americans, Hispanics, Asians and Native Americans. The plan evolved by developing a list of minority organizations and businesses, then writing to these groups promoting IL services and scheduling presentations when possible. IIILC also attended minority events, providing assistance and participation in programs. Minority organizations were included on the newsletter list, and all information on the center's activities was distributed to places where minorities gathered. The results were a significant increase in the percentage of minorities served by IIILC and the addition of another minority board member.

Awards were not presented in the priority areas of housing and accessibility due to the number, status and quality of the applications received in those areas. Monographs, however, will be developed covering those areas, and those priorities will be used in the demonstration sites.

One of the significant aspects of ILRU Exemplary Rural Practices is the utilization of the practices recognized. ILRU will select six demonstration sites and assist those sites in the implementation of one or more of the priority area practices. Two sites will be chosen in an isolated rural area, two sites in a rural area and two sites with offices in a suburban locale, serving rural consumers. Another criterion will be the "fledgling" status of the practices chosen by rural centers. The demonstration site must develop a practice in the absence of a practice for that particular priority. ILRU can not assist in the improvement of a practice. Other criteria center around the prospective demonstration site being a "bona fide" independent living center: it must serve cross disabilities; provide a minimum of the four core independent living services; and encourage consumer control, with people with disabilities representing at least 51 percent of the board, a manager with a disability and consumer participation in program planning, evaluation and elections. Selections will be made by September 1.

ILRU will provide some financial assistance, technical assistance, materials and hopefully some staff time to start practices in these six rural sites in September. A visit will be made for a needs assessment and preliminary discussions on the practice or practices each center may need. ILRU will work with the center during the fiscal year (October through September) so the practice may be in place at the project's end.

ILRU also plans to write a monograph on each of the priority areas, giving four or five alternative practices that are replicable. Included in this "how to" monograph will be a directory of independent living centers and technical advisers who will be able to advise and assist rural centers in each of the priority areas.

ILRU is dedicated to assisting independent living centers in rural settings to serve their consumers according to their needs. This project offers the means of program expansion into areas new to most rural centers.

For more information contact the Research and Training Center on Independent Living, The Institute for Rehabilitation Research, 2323 South Shepherd, Suite 1000, Houston, Texas 77019; 713/520-0232, 713/520-5136 (TT), 713/520-5785 (FAX).

AMERICANS WITH DISABILITIES ACT

Earl Walden, Program Associate (Presenter)
Research and Training Center on Indepenedent Living

The Americans with Disabilities Act, signed into law by President George Bush on July 26, 1990, provides a great opportunity for people with disabilities to enjoy employment and services previously unavailable to them. The ADA also puts a tremendous responsibility on organizations that serve people with disabilities to provide accurate and timely information concerning the ADA to those they serve. Independent living centers, since their inception, have always been in the forefront of service to people with all disabilities. Therefore to fulfill their historic mission, these centers need to have the expertise to provide information that will permit their consumers to avail themselves of the provisions of this law to the greatest extent possible. Also incumbent on the centers is the responsibility to provide information to those employers and public accommodations that sincerely want to provide the services required by the ADA.

Independent Living Research Utilization (ILRU) is currently engaged in a project to determine the information on the ADA available to the centers, the gaps in the informational system, misconceptions concerning the ADA, the resources available for this information and common questions about the ADA from consumers and the business world, as well as compliance information for both consumers and businesses.

The procedure involved in this project led ILRU to select a sample of independent living centers from across the United States with variety in location, size, wealth and ethnicity of consumers. A pre-test was developed for the sample group of ILCs and an equivalent number of independent living staff members not in the sample group. ILRU's plan is to supplement the materials, training and technical assistance of the sample group to see if the provision of materials, information and training developed specifically for independent living centers will elevate the sample's knowledge and service above the norm.

This research information is given only to establish a background for the presentation and demonstration that will follow. ILRU would like to show you a computer program for responding to ADA inquiries we are developing and would like to share with you some of the most successful practices in ADA services delivery by the sample group referred to above.

The computer program is designed to meet inquiry needs at four levels of complexity. The materials, taken from the statute, regulations, interpretations and technical assistance manuals, will be indexed by topic so the inquirer may find the definition and examples of a topic in the least complex screen. Additional information, available directly through that original screen, can address types, procedures, requirements, exclusions, sources, funding resources and compliance issues. Information ranges from introductory to mastery levels.

The major part of this presentation will be a "hands-on" demonstration of the program. ILRU will send a lap-top computer so that as many participants as possible will be able to use the demonstration program. (Note: This IS NOT a sales promotion; the program must be tested through the sample group and modified as determined by on-site usage.)

The second part of this presentation will be the description of four or five successful ADA service-delivery practices and techniques. We are currently working with our sample group to complete the descriptive and final selection of those to be presented. Major factors in the selection process include cost, outcomes, preparation time and replicability. This topic should generate a discussion among the participants about the ADA technical assistance services they offer.

For more information contact the Research and Training Center on Independent Living, The Institute for Rehabilitation Research, 2323 South Shepherd, Suite 1000, Houston, TX 77019; 713/520-0232, 713/520-5136 (TT), 713/520-5785 (FAX).

COMMUNITY SERVICE NETWORKS AND SUPPORTIVE HOUSING: CONSUMER MODELS IN RURAL AMERICA

Stephen Vander Schaaf, President/CEO
Accessible Space, Inc.

Introduction

Rural America's lack of accessible, affordable housing with supportive living services is well-documented, and is the reason many individuals with disabilities "choose" to relocate to cities. In the 1980s new construction programs for individuals with disabilities were slashed by 70%! Unfortunately, the situation has not improved, and the Bush Administration's FY 1993 budget calls for another 53% cut. In real terms, this translates to a total of 870 newly-constructed accessible, affordable apartments for the entire U.S. in FY 1993.

Strategies

One consumer strategy to counter these draconian reductions marshals an array of community resources to modify or adapt existing low-income housing. Virtually every city, municipality, county and/or parish in America has a public housing agency (PHA) or housing and redevelopment authority (HRA). These agencies manage the nation's largest source of low-income housing (apartment buildings and scattered residential homes). Due to recent demographic changes, many of these buildings are shifting from a 90-95% elderly population to 70-75% elderly. The remaining population consists of non-elderly individuals with disabilities, posing "integration" issues for local housing authorities and offering consumers an opportunity to access affordable housing.

Through PHA's and HRA's, consumers access under-utilized affordable housing and combine forces with the housing agency to get accessibility or "mod (moderate) rehab" funds from the Department of Housing and Urban Development (HUD). Assistive funds for "amenities," such as infrared security and personal assistant call systems, are available from Community Development Block Grants (CDBG), foundation/corporate sources and even rural economic development monies. A consortium of funding sources can finance one-bedroom apartments 20% larger in area (640 sq. ft. compared to 545 sq. ft.) than HUD usually allows under its Section 811 new construction program. Adding a consumer-managed, shared Personal Assistant Service (PAS) delivery system makes this approach a triple winner: the housing agency fills its vacant units, consumers receive accessible, affordable apartments, and shared Personal Assistant Services ensure access to care.

Another approach is to accept the challenge of developing accessible and affordable new housing. The awesome prospect of generating new housing and taking on such a long-term responsibility leaves some organizations in endless committee meetings. Other community service networks and independent living centers, such as the Southeastern Minnesota Center for Independent Living, Inc. (SEMCIL) in Rochester, Minnesota, have "pushed the envelope" and sponsored significant new accessible housing in rural America. Atlantis Community, Inc., in Denver is another community service network working with the difficult but "do-able" issue of affordable, integrated housing. Still other groups across rural America are developing co-housing projects based on models in Denmark and European PAS cooperatives.

Common traits of the more successful community service networks - at least in the area of supportive housing - are a healthy competitiveness and creativity. Competition may seem unhealthy or too "corporate America" to the nonprofit human service agency, but understanding the numbers clarifies the need for competitiveness. For example, in HUD's Region VIII, which covers a six-state area (Montana, Colorado, North Dakota, South Dakota, Idaho and Wyoming) only 33 units of new supportive housing for individuals with disabilities will be funded in 1992. **A unit is a one or two-bedroom apartment**, not a separate project -- 33 units for six states and for **all** disability groups. It is extremely competitive at all levels -- planning, financial, departmental, political -- the network must be free of self-interest and flexible enough to respond effectively to such a limited opportunity.

Building Momentum: Missoula, Montana

Missoula, Montana, has an excellent example of a consumer-driven community service network. In 1988, a Missoulian with a disability decided to address his community's need for accessible, affordable housing and 24-hour, shared PAS. Remembering a Minnesota friend from rehab 25 years earlier, the Montanan climbed into his van and drove to St. Paul to learn more about the nonprofit Accessible Space, Inc. (ASI).

After visiting his friend, touring ASI and meeting with ASI's Executive Director, this Montanan returned home to raise some seed money. He convinced the community, and the Rural Institute on Disabilities, to "take a chance" on making a small investment. The Montana Mobility Impaired Housing Project was conceived from this consumer base/community/Rural Institute "friendship," and developed over the next four years.

Eventually five nonprofit organizations became involved, as well as the City of Missoula, the U.S. Department of Housing and Urban Development, and Montana's Department of Social and Rehabilitation Services (DSRS). Four years of persistence, commitment and faith resulted in a beautiful, 24-unit apartment building with consumer-managed PAS. The momentum grew; along the way a consumer in Great Falls, Montana, became interested and initiated his own supportive housing development in that city.

Conclusion

William Blake once said, "Energy is eternal delight," a statement particularly relevant to community service networks and supportive housing models in rural America. In Missoula, no supportive housing for individuals with mobility impairments had existed in the Five Valley Area and no shared PAS delivery systems were available prior to 1988. Yet through the persistence and commitment of one, then two, then many individuals, the vision became reality. Systems changed; undeniable and irresistible momentum accelerated to meet the basic human need for shelter.

Each of many success stories in the United States and Canada shares a common trait: commitment to the goal. Strategies to build momentum take many forms, but all successful rural community service networks approach the goal by recognizing available resources and mobilizing additional support. A "win-win-win" strategy for consumers, funders and providers is effective when resources are limited. The credible network also accepts responsibility for the vision, its implementation and long-term maintenance.

Vision, persistence, mobilization, risk-sharing, creativity, responsibility and above all, energy -- these are the fundamental characteristics of any successful consumer service network. Combined with a healthy dose of social entrepreneurship, they can change, empower and educate any community.

For more information contact Stephen Vander Schaaf, Accessible Space, Inc., 2550 University Avenue West, Suite 301 North, St. Paul, MN 55114; 612/645-7271, 800/466-7722, 612/645-0541 (FAX).

HOME ACCESSIBILITY

Sallye Lemons, Independent Living Services Coordinator and Specialist (Presenter)

Disabled Citizens Alliance for Independence, Inc., provides many services, including home modifications.

We assume the traditional practice is considered to be a referral to vocational rehabilitation for services under the 110 program or independent living monies through Title A funds. In some instances we do utilize VR programs; however, not everyone qualifies for 110 services. The waiting list for IL monies is long, and the need for assistance is immediate.

If a consumer has the financial resources for home modifications, we provide the technical assistance they need to complete home modifications. The following procedure is used for the consumer who is not eligible for assistance through existing programs.

In a rural setting, with limited business resources for donated materials (lumber yards, hardware stores), our staff has developed a network of resources for the construction of ramps. The resource is "mills" -- pallet, wine vat, mine props and post mills scattered throughout our service area. After a blueprint/sketch is developed and a list of needed materials is compiled, the list is divided among available mills. Mill owners are then contacted and a request is made for a specific number of supplies. This way, one small business owner is not being asked to donate all the materials for a project.

Whenever possible, we order wood preservative, nuts and bolts, and other materials through NAEIR, a Galesburg, Ill., distribution center for manufacturers' excess inventory.

Ramps built with rough-cut oak will last longer than kiln dried lumber, especially when treated with wood preservative, used motor oil or antifreeze. Therefore, ramps built with mill donations are more durable than those built with materials purchased from traditional sources.

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It is our policy to provide services to everyone who calls if the requests are within reason. In our last completed fiscal year, 2,612 people received services under our basic grant, and 1886 received services under our expansion grant. Our numbers increase every year. A major portion of our consumers have spinal cord injuries, cardiovascular conditions, arthritis, visual impairment or impaired hearing. But we serve all types of disabilities and all age groups.

We are not aware of our program being replicated in other communities. By using community resources and dividing the request for materials, we eliminate the cost of materials.

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Our impact on consumers can be simply stated: They have access to the world beyond four walls.

Our approach is particularly relevant to rural service delivery, as we are utilizing local resources that are predominantly rural in nature. By developing a plan to obtain building materials from more than one source, we reduce our out-of-pocket expenses, which in turn allows the Center to meet more of the consumers' needs.

For more information contact the Disabled Citizens Alliance for Independence, Inc., P.O. Box 675, Viburnum, MO 65566; 314/244-3315.

ALTERNATIVE FUNDING STRATEGIES

Mike Schafer, Executive Director (Presenter)
League of Human Dignity

Our **vehicle-conversion program** is a separately structured entity that we use to help fund our Independent Living Center. It is not separately incorporated -- it is under the same structure as the League -- but it is considered a for-profit division of the League.

It really was an existing business, located in Carter Lake, Iowa, that a man started in response to his son's injury by an ultra-light plane accident. His plan was that he would start this business and, of course, his son needed a vehicle so he was going to modify that vehicle and then build up the business for his son to run. But his son wasn't really interested in it. So the man that owned it offered it for sale.

Of course, we were interested in the business, but we couldn't afford the asking price. That was probably six or seven years ago. We just kind of kept our eye on it and when we would hear that he was starting to get motivated to sell again, we would contact him and see what he was asking for it. We eventually bought it for the cost of the inventory and equipment we wanted. It took us probably a year of negotiations before we came to terms.

We took it over in September of 1990 and moved everything down here. He just closed his shop up there and we moved everything, eventually renaming the company Mobility Options. Essentially, what the business does is provides modifications to any vehicle that a person with a disability would need to have modified in order for them to drive, or for schools, families or transit authorities to modify for transporting people with disabilities. We are vendors or dealers for about 300 manufacturers -- including all of the major lift manufacturers and some minor ones.

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Our goal with this program was really twofold: We wanted a source of revenue that we had some control over that would hopefully generate a profit to fund our nonprofit activity.

We had projected the first year that we would not make over $100 profit and in reality, we made several thousand dollars profit the first year. And it is continuing to grow. I think we will probably even put some sales people on the road and try to market more in Kansas, Kansas City, Iowa and the surrounding area.

I think that in another three years, the business will return $50,000 to $60,000, with more potential beyond that. We are really considering doing some strategic planning now and I think we may eventually get into vehicle sales.

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The people who use our service run a fairly broad spectrum of mobility impairments, ranging from simple hand controls on an otherwise standard automobile to major kinds of modifications. We are currently working with a woman who has no function in terms of being able to turn a steering wheel. So, we are working with her to try and get the state to fund a digi-drive system which is a joy stick-operated driving system.

In a typical case, someone will come to us and say, "I want to be able to drive." If it is fairly obvious to us that there is a functional ability there, we do an evaluation based on how they are going to use the van, the particular wheelchair that they will be using and whether they want to drive from their seat or their chair. We know what kind of equipment and what kind of vans are best for driving from the chair.

It is best for people to come to us before they purchase a vehicle, but unfortunately there are some instances when they already have a vehicle and it's the wrong one. At that point, we try to make the best of the situation.

For more information, contact the League of Human Dignity, 1701 P Street, Lincoln, NE 68508; 402/471-7871.

THE COMMON THREADS

- **Equal access needs to be seen as a right**, not an option. For people with disabilities, access is an educational and systems change issue. The first step is to teach people and organizations in the community, **using everyday, jargon-free language**, why equal access is important and how to achieve it. Disability issues need to be integrated into the mainstream of community life, because the need for access affects many different groups in rural communities. Get involved in community-wide issues affecting children, minority groups, elderly people, and low-income people.

  One way to recruit a broad base of support is to form disability awareness committees to work to **change unfavorable community attitudes about disability and access**. Awareness committees can inform people about the Americans with Disabilities Act (ADA). Then the enthusiasm of just a few ADA "converts" can infect other community members and get the ball rolling. Although "Dare a Disability" days can be controversial, they can also be effective awareness tools in some situations. The focus should be kept on "barrier awareness" rather than "handicap awareness."

  You can also work with the your local public library to build a resource collection of disability-related materials. Join your local Chamber of Commerce, too. It's a great place to share information with other people interested in disability issues. **Whether it's a major construction project with designed-in accessibility or a local restaurant providing picture and braille menus, always remember to publicly honor your local "accessibility heroes and heroines."**

  Consumers, their friends and family members must learn to be self-advocates on accessibility problems. As the people most directly-affected, they should be the ones to approach local businesses, local government and other organizations about the importance and urgency of access. Advocacy should come from consumers up, with consumers (not programs) planning accessibility goals.

  Consumers can tell their personal stories to illustrate the need for accessibility in frequently-used buildings (post office, library, drugstore, local government buildings, etc.). Consumers and disability service providers can team up to offer architectural access audits to local businesses and others. **County agricultural extension service agents are rural experts with many skills,** and could also be trained to conduct accessibility surveys. Perhaps the need for accessibility could be used as a welcome justification for new construction or a long-postponed renovation.

  Respect for cultural traditions is important, because the local culture may influence who gets accessibility modifications and how modifications are used in the community. Since the ADA doesn't apply to people living on tribal lands, community leaders and people with disabilities who live on reservations may want culturally-sensitive awareness training on the rights they have off the reservation and the access needs of people on the reservation. (For more information related to Native American issues, see the synopsis of the Native American Forum later in this document.)

- Common Threads '91 participants listed the lack of rural transportation as a major access problem. **Transportation is still a major access problem for all rural areas.** Westerners are sometimes accused of "Western Chauvinism" (sort of an "Our roads are worse than your roads!" attitude), but Northerners, Easterners, Southerners and Midwesterners also put up with rural unimproved roads, unpredictable weather and geographic barriers. There are creative ways to cope. Try **bartering or trading services among providers of disability or nondisability services.** Put wheelchair lifts on existing vehicles. Offer your transportation service to everyone in the community and charge a fee for service to all users. Your local hospital, clinic or nursing home may maintain accessible vehicles that could be shared. Insurance and liability problems can be avoided by: 1. paying consumers and/or their families to hire their own transportation services; 2. paying volunteers a small stipend to provide transportation (personal liability insurance rates are lower); or 3. bartering for services.

- **You can have accessible rural housing, but it requires creative funding.** There are ways to fund nontraditional construction. For example, the Farm Home Administration has a 10 percent set-aside for nonprofit agencies. Look beyond both the Section 202 program, which provides rental housing for the elderly (Housing and Community Development Act of 1987), and Housing and Urban Development funding; become familiar with the Community Reinvestment Act, in which banks are required to invest profits back into the community. Emphasize that there is a growing market for accessible homes as you network with interested real estate developers. With support, some people can build their own accessible homes. (The Research and Training Center for Accessible Housing at North Carolina State University, School of Design, Box 8613, Oberlin Road, Raleigh, NC 27695-8613, 919/737-3082, is a good resource.)

- **Access to services** begins with integrated daycare, respite and early intervention services. Rural people with disabilities also need access to substance abuse treatment and mental health services. **We must work together to develop adequate funding for personal assistance services,** long-term care services, transition planning/services, assistive technology, sign language interpreters, independent living skills training, and peer support. Paraprofessionals might be trained to provide at least some of these services in rural areas. Although assistive technology can enable rural people with disabilities to live more independently, we have to take care that it doesn't also limit their day-to-day contact with other people. People with disabilities need to be able to choose from an array of high and low-tech assistive technology options. Rural ingenuity networks can make and share assistive devices. (Contact your state's assistive technology program. Forty-three states now have them and they all have a mandate to work on access to services in rural areas.)

  Rural people with disabilities also need **access to information (use your local library creatively)**, access to income, and access to both generic and disability-specific services. **It's important to know what services are available in your area, so you can network with local service providers, churches, schools and libraries.** State agencies can coordinate their activities to ease accessing all state-supported services.

- **There are other ways to access funding beyond the traditional funding resources.** A word of warning, however: Avoid "saturation" in very small communities -- don't repeatedly ask the same people, organizations, and/or businesses for donations. Every community has people with financial expertise. Why not ask one of these financial "mentors" to help write your funding requests? Your local social security and county welfare personnel can be powerful allies, so nurture your relationships with them. At times, you may have more current information about their programs than they do, so be sure to keep them informed. Serving on interagency councils can help you both become aware of funding options and inform other agencies of your organization's needs.

  When you buy assistive technology, ask the vendor to help write the request for Medicare or Medicaid funding; vendors know how requests should be phrased. Strategies for funding assistive technology can apply to funding other services as well.

  "Ask and ye just might receive," but **don't become just another "charity." Always give something in return for the help you receive.** Cohesiveness and shared viewpoints result through the give and take of reciprocity. Collaboration may be the key to accessing some funding sources and avoiding duplication of effort.

- Try to organize as many different groups as possible to focus (especially in the beginning) on a single access issue, and make sure that you all share the same goal before you go public. Work to change state and national funding laws through organized political action. Medicare and Medicaid should be encouraged to respond preventively and holistically to a person's needs. In rural **Wisconsin**, for example, a man who uses a wheelchair needs a special chair insert to protect his sensitive skin and allow him to work more hours at his job. When he doesn't work, he becomes self-abusive and is in danger of blinding himself. Although Medicaid pays for his wheelchair, it won't pay for the preventive protection of a chair insert. Consumer accessibility coalitions can be empowered to influence funding by testifying before the state legislature. Your local legal community may provide mentors who can help organize class action systems change appeals.

In Summary

Keep on **fighting negative individual and community attitudes while retaining your personal and group positive attitudes.** Don't give in to radical attitudes and unrealistic expectations. Build on successes, use diverse approaches, and grow through self-education. Barter, trade and work together for an inclusive community.

Rural Strategies

Viburnum, **Missouri**, is totally accessible, thanks to a "neighbor helping neighbor" program. For more information contact the Disabled Citizens Alliance for Independence, Inc., P.O. Box 675, Viburnum, MO 65566; 314/244-3315.

Access **Alaska**'s "Hammer Project" works with the local carpenter's union and donated materials to complete home accessibility modifications. (See 1991 Common Threads Proceedings.) Unions don't usually object to projects being completed by high school shop classes or by persons doing court-ordered public service.

A rural disability service program sells advertising in its newsletters and uses that income to maintain an assistive devices loan bank.

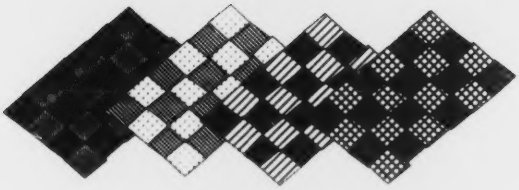
In **Georgia**, Part A (Title VII of the Rehab. Act) funds, which are allocated to the state for independent living center services, have been granted to consumer groups for ramp construction.

Oregon has a cigarette tax that funds transportation, including that of individuals. Funds can be used to purchase transportation services or personal vehicles. One funding strategy you might pursue is a cigarette tax earmarked for public accessibility modifications.

4-H clubs can sponsor accessibility obstacle course activities.

An organization of wheelchair users "kidnapped" the mayor of their town, put him in a wheelchair and let him experience the obstacles involved in navigating their community. They quickly got the curbcuts for which they'd been asking.

Montana's independent living centers have launched a "Burlap Bag" campaign in which postpaid postcards are sent to consumers asking them to list personal and community access needs. Burlap bags will be filled with cards and taken to the state legislature as graphic evidence of need.



NETWORKING PARTNERSHIPS

The essence of **NETWORKING is making connections, then forging those connections into relationships that nurture mutual interests.**

The essence of **PARTNERSHIP is sharing, participating and agreeing that everyone involved is playing on the same side or team as everyone else.**

Even if it's not part of a job description, making connections in rural areas is vital. Most people can't do their jobs without an extensive personal and professional network of friends, colleagues and community contacts.

One of the 1991 "Common Threads" recognized that, **"Although much rural networking is done at a personal level, formal working relationships are also necessary to clarify expectations and to satisfy outsiders (such as funding agencies)"** (Common Threads Proceedings, 1991). Indeed, some tasks won't be accomplished without the more formalized partnerships that often result from informal networking. Some people are adept at linking individuals and groups who might not immediately recognize their common interests. Others are skilled at crafting the interagency agreements that formalize informal arrangements. Everyone facing rural disability challenges needs to be a good networking partner.

Common Threads '92 looks at some successful rural networking partnerships, formal and informal, personal and professional. Identifying networking strategies is sometimes difficult because we frequently take our day-to-day networking activities for granted. The best formal partnerships usually evolve from friendly everyday networking.

3

BREAKING NEW GROUND: CULTIVATING RURAL RESOURCE NETWORKS

Barry Delks, Rural Rehabilitation Specialist (Presenter)
Gary Stoops, Outreach Program Coordinator (Presenter)

The **Breaking New Ground** Outreach Program (BNG) provides a variety of services, including information on assistive technology, case management, farm site evaluations and numerous service and resource referrals for Indiana farm families with physical disabilities. Funding for the BNG Outreach Program comes from a cooperative effort: USDA AgrAbility Projects, Indiana Easter Seal Society, the Indiana Department of Human Services (vocational rehabilitation) and private contributors. Purdue University provides the base of operations.

Strategy

The BNG Outreach Program seeks to build a strong "grassroots system" of rural professionals, service providers and client support networks by weaving together existing groups and organizations. Being a part of the Agricultural Engineering Department and Cooperative Extension Service of Purdue University allows the BNG Outreach Program to access a wealth of agricultural related research and university professionals as well as a statewide educational communication system. The staff consists of a director (also state safety specialist), an outreach coordinator, a rehabilitation engineer, an information specialist, a rural rehabilitation specialist, a 4-H specialist, an agricultural education (Ag-Ed) specialist and six graduate research assistants who interact on a variety of service delivery projects.

Because BNG comprises a wide diversity of staff backgrounds representing many different campus departments, each with their own affiliations, an immediate networking system occurs. The BNG staff operates within grassroots networking systems that involve the Cooperative Extension Service (every county has at least one 4-H youth agent, ag agent and home economics agent); Ag-Ed/FFA teachers (nationally, there are approximately 8,000 such teachers working with over 400,000 students); professional organizations (Indiana Association of Rehabilitation Facilities, ATTAIN Group, Easter Seals, etc.); local and national farm groups (Indiana Young Farmers Association, Farm Bureau, Grange, etc.) and literally thousands of individuals through on-site service visits and our public awareness and educational programs.

Method

The BNG Outreach Program staff has developed a proactive, comprehensive approach to reach the agriculture/social service leadership in all 92 counties of Indiana. The three elements of integrating community resources include:

I. Professional Networking

A. Extension agent contact and training
B. 4-H leader and Jr. leader training
C. Ag-Ed teacher training and lesson plans
D. State vocational rehabilitation contacts and training
E. NIDRR State Technology Grant affiliations: ATTAIN (Accessing Technology Awareness in Indiana)
F. Publishing the Indiana Directory of Disability Resources
G. County extension office site visits by staff and client/farmer liaison
H. Electronic mail to all 92 county extension offices
I. State safety training by our rehabilitation engineer

J. Presentations to hospitals and school staff: OTs, PTs and social workers

K. Presentations and site visits with State Employment Agency personnel

II. Client-based Networking

A. Barnbuilders: a state/national client volunteer assistance network
B. Direct contact with clients: County Ag Days, fairs and machinery shows
C. Two newsletters with state and national distribution
D. Support group meetings
E. Client/Farmer Mentor Program
F. Farm visits for consultation and evaluation

III. Public Awareness Networking

A. Indiana Easter Seal Telethon and newsletter
B. Newspaper/radio/magazine articles
C. Assistive technology demonstration van, modified tractor and wheelchair awareness course at fairs, shows and Ag Days
D. Brochures and public service announcements
E. Campus/sorority fund-raisers
F. Presentations to farm organizations and clubs

Case Study: Professional Networking

Training

On April 8, 1992, Bill Field (Director of BNG), Ed Bell (farmer liaison for Easter Seals) and Barry Delks (Rural Rehabilitation Specialist for BNG) went to the annual Spring Agricultural Extension Agent Training at McCormicks Creek State Park. Field presented general information about BNG and the services it provides. He distributed BNG resources (including the Indiana Disability Directory and Involving Individuals with Disabilities in 4-H) to the extension agents. He also gave an overview of clients' needs and how extension agents might assist farmers with disabilities.

Bell, owner of a 90 acre U-Pick vegetable operation, was next on the agenda. He shared how farming with a spinal cord injury is possible. He also discussed BNG's plans to visit county extension offices and 4-H fairgrounds to provide on-site accessibility evaluations and discuss the Americans with Disabilities Act.

Finally, the agents were dismissed from the meeting room to go outside to see the BNG van. Delks demonstrated the BNG van, assistive technology and various resources available to assist farmers with disabilities.

Networking

By providing training for agricultural extension agents an immediate connection was developed with all 92 counties in Indiana. The extension agents have an extensive grassroots network within each county consisting of an extension board of directors, 4-H boards, home economics groups, pork producer groups, beef producer groups, county planning and zoning boards, county commissioners, farm bureau groups, civic organizations, chambers of commerce, school systems and, of course, the hundreds of individual rural and farmer contacts made through educational training and individual farm visits.

Collaboration

The extension agent training literally resulted in thousands of contacts with the rural population of Indiana. Within two weeks of the agent training, more than 10 percent of the counties had requested on-site accessibility assessments of their county government buildings and 4-H fairgrounds. More requests for the BNG van at county fairs came in than we could accommodate. Numerous requests for Ag days, field days and educational material came in as a result from the training.

Resource Development

Within a few days of the training it was evident that our staff would not be able to accommodate the demand for on-site accessibility assessments and information on the ADA. In response to the calls, Dean Brusnighan and Delks developed a letter, an ADA resource sheet, a list of consultants available to do on-site assessments and a copy of the PVA publication, "Accessibility to Public Accommodations."

Once these resources were produced, D. Petritz, assistant director of cooperative extension services, was contacted. Petritz enclosed our packet of ADA resources in a mailing to all 92 county extension offices on April 29, 1992.

Critical Steps to Success

In this specific situation there were several critical steps that made this an effective rural networking project:

1. Once the agricultural extension agents "expressed a need" for ADA material and on-site assessments, the BNG staff responded in a timely matter. Written resources on the ADA, practical steps for the extension agent to initiate planning, a list of consultants for on-site assessments and agencies available for free consultations were all developed.

2. The BNG staff responded to client's needs through other rural professionals (existing community support system). The individuals (disabled farmers, zoning and planning boards, chambers of commerce, county commissioners, extension boards and 4-H boards) all needed information on the ADA and received it from BNG through the local rural network (county agents).

3. Contact with local and state extension staff provided an immediate grassroots network that quickly disseminated the information to farmers, 4-H youth, home economics groups, county officials and literally hundreds of individuals throughout the state.

How to Implement Similar Models

1. Initiate and develop relationships with state extension staff (agricultural, 4-H and home economics).

2. Provide extension agent training, news articles, resources and 4-H materials.

3. Develop quality resources to meet an expressed need in a timely manner.

Case Study: Client Networking

Background

Dan slipped on ice while adjusting a tarp on his semi-trailer truck, resulting in a T-10 spinal cord injury. His state vocational rehabilitation counselor suggested he contact BNG's Outreach Program for resources on farming with an SCI. Dan was visited within two weeks, and a work-site assessment identified 15 recommendations for his farm, home and retail seed corn business. Dan's counselor worked closely with BNG, followed the recommendations provided and funded special equipment costing thousands of dollars. These items allowed Dan to perform many of the farming tasks he did prior to his injury. BNG has continued to work with Dan on restructuring other tasks, especially in his seed corn business, to develop methods that are cost effective, timely and safe. BNG has in turn gained valuable feedback from Dan on the effectiveness of the technology and task restructuring. Dan's willingness to work with BNG and his ability to relate his unique experiences have opened networking possibilities in several areas:

1. Dan has responded to calls, through BNG, from other farmers who need information on seed handling equipment, planter filling techniques, bulk seed purchasing and other adaptations. The resulting exchange of information helps both parties.

2. New technologies and products were loaned to Dan for his evaluation and feedback. A longtime manufacturer of automobile hand controls developed a set of controls for an ATV that uses pedals and steering wheels similar to those of a car. At the request of the manufacturers of the controls and the ATV, BNG contacted Dan to try out the vehicle and its hand controls. His suggestions on the operation and placement of the controls, as well as additional accessories and modifications to the ATV, have helped to increase its usefulness and availability to a new group of people.

3. Dan's offer to help has also extended to public awareness events. He allowed BNG and Indiana Easter Seals to feature his farming operations in a statewide telethon segment. Dan was interviewed by an Indianapolis TV Agriculture reporter and filmed while operating his modified farming equipment. Later, Dan was interviewed during a live telethon featuring his experiences and his involvement with BNG and Indiana Easter Seals.

Training

By identifying clients like Dan who are willing to help and by developing a grassroots peer support network such as "Barn Builders," volunteers are trained in relating one-to-one with farmers and other individuals who are coping with similar problems. Areas of assistance can include personal feelings, family dynamics, financial options, alternative enterprises and technical questions. Support networks can be through individual farm visits, hospital visits or in group settings like supper meetings and conference gatherings.

Resource Development

Equipment evaluation was enhanced tremendously by working with Dan on the ATV/hand control testing. The situation opened a dialogue with both of the manufacturers, thus boosting their awareness of the unique problems of paraplegic farmers/riders. Dan's views on farming with SCI were demonstrated in the telethon segment and increased public awareness of what can be accomplished with assistive technology on the farm. The uniqueness of the film has resulted in an expanded version of another clients's story to be scheduled for the National Easter Seal Telethon audience.

Results

The BNG Outreach Program averaged between 90 and 100 farm visits for consultation, information and evaluation each year since 1988, working with an average of more than 80 individual clients. Hundreds of phone calls, letters and publications, as well as thousands of public contacts, are recorded yearly. Our direct referrals to state vocational rehabilitation and other service agencies have resulted in many farmers receiving financial aid for equipment modifications. Case management and follow-up services seek to provide the resources that farmers with disabilities need.

It has been demonstrated that when agriculture and social service community leaders are informed and knowledgeable of BNG's services and aware of the need for those services (17 percent of Indiana farm families are affected every year by a disabling condition), together we can serve the rural population of Indiana more effectively.

For more information contact The Breaking New Ground Resource Center, 1146 Agricultural Engineering Bldg., Purdue University, West Lafayette, IN 47907-1146; 317/494-5088.

EARLY INTERVENTION IN RURAL NORTHERN ARIZONA

Diane Lenz, Early Intervention Coordinator (Presenter)
Linda Contrucci, Early Intervention Specialist (Presenter)

The **professional literature** on early intervention highlights the importance of early identification and treatment in reducing the impact of disability on children and families. The federal government recognized this and passed P.L. 99-457 in 1986, making money available to states for planning coordinated early intervention services.

P.L. 99-457 stipulates that early intervention services be family-centered; the focus is on the family as the primary support for a child's development. The law intends that the family of a young child with special needs receive services that maximize the child's strengths and facilitate his/her development.

The Institute for Human Development (IHD), a University Affiliated Program at Northern Arizona University in Flagstaff, has provided early intervention services in rural northern Arizona since the mid-1970's.

The IHD provides early intervention and related services for children birth to three years of age, and their families, who live in Flagstaff and on the Navajo and Hopi reservations. The IHD currently serves up to 50 children with disabilities or who are at risk for developmental delays. Delays in development range from mild to severe and may be related to factors such as prematurity, mental retardation, Fetal Alcohol Syndrome, or cerebral palsy. Services are family-oriented and usually provided in the home.

In Flagstaff, graduate students and the Early Intervention Coordinator provide service coordination and home-based early intervention for children. Services are provided in individual and small group settings.

This discussion focuses on the project's Outreach program on the Navajo and Hopi reservations. The Outreach program illustrates how a community-based service model can use local paraprofessional staff effectively.

Geographic and Cultural Considerations

The IHD Outreach model for early intervention developed over ten years, in response to the geographic, linguistic, and cultural characteristics of northern Arizona.

Flagstaff, Arizona (elev. 7,000 ft.) is a community of about 43,000, located at the base of the San Francisco Peaks. It is the major "metropolitan" area in northern Arizona. The geography of northern Arizona includes deserts and mountains, and the climate can be extreme. Snow, mud, and unpaved roads complicate service delivery to remote reservation communities. The IHD Early Intervention Project serves three counties encompassing 39,847 square miles, with a population of about six people per square mile.

Northern Arizona culture varies as much as its geography. Outreach Program paraprofessional Instructional Aides on the Hopi and Navajo reservations live in, and speak the language of, the communities they serve. Speaking a family's native language, the Instructional Aide helps the child learn skills more easily and helps parents understand concepts for which there are only English words.

Respect for the balance between traditional cultural practices and family participation in formal services is critical to the success of service programs in multicultural setting. For example, the family of a child with dislocated hips might choose to follow the advice and practice of a traditional medicine man rather than pursue Western medical intervention. Outreach Program professionals and Instructional Aides must reserve any personal influence and judgment and preserve the family's right to choose.

The IHD Early Intervention/Outreach Model

The IHD Outreach early intervention model evolved from University-based professionals' efforts to provide services to young children and families in rural northern Arizona communities. This city-based professional program was expensive, and contact with families was infrequent. Travel distances, inadequate telephone services, and cultural and language barriers hindered consistent, family-focused intervention.

Today, Instructional Aides are based in six very diverse northern Arizona reservation communities. The aides provide home-based intervention within a 60-mile radius from their own homes. Schedules are determined by the number of families assigned, the distance to each home and how often the children are seen. An Early Intervention Specialist from Flagstaff travels about 1500 miles each month visiting service sites.

Establishing Early Intervention Service Sites in Rural Reservation Communities

The IHD's paraprofessional model develops programs specific to the needs and available resources of each community, according to four steps:

1. Identify and evaluate children with disabilities within a 60-mile radius of a rural community. Identify children with significant delays through phone conversations with community health professionals, Head Start staff, school personnel, and Arizona State Division of Developmental Disabilities staff. Identify important Tribal agencies which should be informed and involved in the project. Visit the community to confirm the eligibility of children recommended for services. Forward referrals to the Division of Developmental Disabilities for confirmation of eligibility.

2. Hire and train local paraprofessional Instructional Aides who are familiar with local culture, speak the local language, and are recognized and trusted. Advertise Instructional Aide positions in newspapers, on bulletin boards at local trading posts, on local radio stations and through word of mouth. Screen written applications for educational background and experience with children (with or without disabilities). In interviews, assess applicants' abilities to work independently, to be innovative and flexible, and to communicate with co-workers and families.

   Instructional Aides are trained in topics which include: developmental checklists implementing Individualized Family Service Plan objectives; data collection; seizure management; philosophy and principles of developmental disabilities; family support; CPR; and first aid. Training is an on-going process including on-site monthly follow-up and supervision by an Early Intervention Specialist.

3. Learn and use the specific resources in each community; this is critical to the success of this program. Does the community have a hospital? Therapists? What transportation exists? For example, in one community, a private agency operates a van to pick people up at their homes and take them to medical appointments.

4. Enable local agencies to take over programs started by the IHD. The IHD initiates and develops services, with the goal of turning administrative responsibility over to community-based agencies. Remain available to support new locally-administered

programs with staff training and technical assistance. As communities become aware of young children's needs and local people are trained to provide quality services, the IHD and the state agency can shift funds to other rural areas in northern Arizona where young children need early intervention services.

IFSP and Program Planning

The Arizona Department of Economic Security/Division of Developmental Disabilities funds the Early Intervention Project and determines a child's eligibility for services. When a child is eligible for services, an Individualized Family Service Plan (IFSP) is developed.

The annual IFSP is a team effort of the children's parents, the Instructional Aide, the IHD Early Intervention Specialist, a Case Manager from the state agency, consulting therapists, and any other people involved in the child's treatment. Curricula such as the Carolina Curriculum for Handicapped Infants and Infants at Risk assess the child's most critical areas of delay.

A young child's needs are inseparable from the family's needs. The IFSP includes a Family Survey which lists common concerns of families with children having special needs. Parents can complete the Family Survey in writing or by interview, and are asked to set priorities for the child and the family.

The Aide has primary responsibility for teaching the child the skills identified in the IFSP. The Flagstaff Early Intervention Specialist visits each of the six service sites monthly and reviews the child's progress with the Aide, to determine if changes in teaching strategy are needed.

Progress toward meeting family needs identified by the IFSP is also closely monitored. Family needs change, as must the strategies for meeting them. Examples of family needs which might become IFSP goals are:

- In one community, the Instructional Aide worked with a women's shelter and Tribal social workers to serve a woman and her two children with disabilities. The woman was threatened with domestic violence and faced a possible divorce.

- In another community, the Aide worked with Navajo Housing Authority staff to get an apartment in town for a family from an area that was inaccessible in winter.

- A child needed medicine that required refrigeration. His family's hogan had no electricity, but did have a small propane tank for a gas stove. The aide succeeded in getting the state disability agency to pay for a propane refrigerator, and convinced the gas company to install a larger propane gas tank.

An annual parental consumer satisfaction survey helps the IHD plan changes in services.

Preschool Transition

P.L. 99-457 allows children as young as 3 years of age to receive public school special education services. Transition from early intervention services, which are usually home-based, to preschool programs, which are typically center-based, can be an exciting, yet worrisome time for a family and child.

The Instructional Aide and Early Intervention Specialist inform parents of the child's right to attend school at age three, and discuss options and provide legal information on preschool placement. The Early Intervention Specialist coordinates transition planning with local education agencies.

When the child is 2½ years old, he or she has a formal diagnostic assessment through the Indian Children's Program (ICP). The ICP Assessment Team is a rather unique local resource available through collaboration of the University Affiliated Programs in Arizona, New Mexico, and Utah. This team generates a comprehensive report providing a child's new school with valuable diagnostic information, teaching strategies, and placement recommendations.

Conclusion

The advantages of this paraprofessional program model for early intervention services are:

1. The Instructional Aides are familiar with the culture, language and geography of their communities.

2. The combined knowledge and experience of the University-based professional Early Intervention Specialist and local paraprofessionals makes an effective team. The Instructional Aides are comfortable with and trusted by families; the Specialist is a professional resource with knowledge and experience of young children.

3. The program employs local people in communities where unemployment is high.

4. The program is cost-efficient. A comparable program using professional staff to serve 30 children living in remote areas would be much more expensive.

5. The paraprofessional program ensures consistent services to families who might otherwise receive limited or no services.

For more information contact the Institute for Human Development, Arizona University Affiliated Program, Northern Arizona University, Box 5630, Flagstaff, A\ 86011 602/523-4791.

[redacted]

INDEPENDENT LIVING IN WISCONSIN FOR OLDER PEOPLE WITH VISUAL DISABILITIES

Don Golembiewski, Project Coordinator (Presenter)

This paper presents an innovative rural Rehabilitation Services Administration project which requires a high degree of interagency cooperation for success. The three key objectives of this project are:

1. Establish a high level of cooperation between two separate service systems - the Wisconsin Aging Network within the Division of Community Services, and the Wisconsin Blindness Rehabilitation Network of the Division of Vocational Rehabilitation (DVR), Department of Health and Social Services.

2. Employ older people, trained as paraprofessional teacher assistants, to provide itinerant, one-to-one support services for older individuals who have blindness or some other visual impairment.

3. Purchase adaptive aids and devices, orientation and mobility instruction, and transportation services for older clients of DVR's Rehabilitation Teaching for the Blind Program.

The overall mission of this project is to expand DVR's Rehabilitation Teaching for the

Blind Program, and extend independence-enhancing services to more older (i.e., 55 years old and above) individuals with blindness or other visual impairment. These services are targeted to individuals unlikely to be employed, but who could feasibly live independently. The project helps older people adjust to living with decreased vision, learn self-care skills, and live as independently as possible in the least restrictive environment. The project's objectives are met as follows:

Objective #1

This project strengthens the relationship between DVR's Rehabilitation Teaching for the Blind Program and Wisconsin Aging Network's services to older people. The collaboration expands outreach of the Rehabilitation Teaching Program; increases availability of visual health screenings, blindness prevention and public information activities; and enhances Wisconsin Aging Service's knowledge, sensitivity, and capacity to better serve older people with blindness or other visual impairment.

DVR and the Bureau on Aging developed cooperative agreements that benefit older consumers with blindness and other visual impairments. Each of Wisconsin's six Area Agency on Aging (AAA) Directors designated a staff member as the Blind Elderly Specialist Technician (BEST). The BESTs are trained on the needs and potential of people with vision loss, and adaptive equipment and strategies that help ameliorate difficulties. The BEST acts as liaison between the two service networks and encourages earlier, more appropriate interventions and cross referrals. The BEST also trains other Aging Network staff in awareness of older people with blindness and other visual impairments, which enables staff to better understand and meet consumers' needs.

The BESTs will also participate in assessing Older Americans Act services administered by County and Tribal Aging Units, to determine if programs are accessible by older people with blindness and other visual impairments. The pilot assessment model will be expanded statewide to comprehensively assess each aging unit's capacity to integrate older people with blindness and other visual impairments into its service system. On-site assessment teams will include the area's BEST, the Independent Living for Older Blind Individuals Project Coordinator, the local rehabilitation teacher, and at least one consumer.

The assessment team will find ways to increase the involvement of older people with vision loss in all types of aging services. Access will be scrutinized at the administrative level (decision-making, training, planning, boards, and committees), the direct services level, (transportation, benefits counseling, and nutrition), and the physical level (architectural accessibility, lighting, large print/braille signage, and adaptive recreational equipment).

The team will recommend necessary changes and will work with the aging unit on specific strategies for improvement. Money is available to each AAA for improving service provision to the target group. Each AAA may use this money (on approval of the Grant Advisory Committee) to train service providers, to buy adaptive equipment, to pay for print enlargement and cassette and braille transcription services, and generally to improve the direct service capabilities of individual county aging units. Each AAA Director will forward a report on the agency's accomplishments and expenditures to the project coordinator at the end of each grant year.

Objective #2

The project will recruit and train teacher assistants (55 years of age or older) to provide basic support for DVR's blindness rehabilitation teachers.

The Rehabilitation Teaching Program for the Blind and Visually Impaired, Wisconsin Division of Vocational Rehabilitation, provides independent living services. It's an itinerant program operating from DVR District offices, strategically located to provide services in every community in the state. The staff of 13 rehabilitation teachers annually serve more than 1,800 people with blindness and other visual impairments throughout the state, most of whom are elderly and not vocationally-oriented. The instructors teach daily living skills, self-care skills, and social adjustment skills to consumers in the consumers' homes.

A teacher develops a rehabilitation plan for each eligible client, which could include one or more of the following skill/service areas:

1. Counseling and guidance
2. Information and referral
3. Provision and use of optical aids
4. Orientation and movement
5. Communications
6. Personal management
7. Home management
8. Library, large print, and transcription services
9. Leisure activities

The Teaching Program's overall objective is to minimize the effects of vision loss on a person's everyday life and to teach him or her the skills and techniques for confident self-sufficiency at home, and continued participation in the community.

The number of older people who are at higher risk of developing vision loss or blindness is growing, and the current number of professional rehabilitation teachers is inadequate to meet the demand. By assuming some of the routine duties, trained teacher assistants allow the teachers to serve more consumers. Also, those teacher assistants in remote, isolated, and rural areas of Wisconsin can respond to local problems immediately, when the teacher might be miles away.

Teacher assistants were recruited through the "Over 55" coordinators at the Wisconsin Job Service, county and tribal aging unit directors, each DVR District Office, and each of the DVR rehabilitation teachers. Trainees attended a three-week session which included information on eye conditions, the medical aspects of aging, related disabilities, adjustment to vision loss, using community resources, and adaptive techniques and equipment used by people with blindness and other visual impairments. Trainee co-teaching using sleepshades and low vision simulators was also an important part of the training. Trainees were hired on the basis of written test and interview performance.

On a referral form, the rehabilitation teacher lists teacher assistant services to be provided as part of the individualized case plan. Delegating routine responsibilities frees the teacher to devote his or her expertise to the more demanding and technical aspects of the plan. The teacher assistant files regular case progress reports with the rehabilitation teacher.

Teacher assistants help professional rehabilitation teachers deliver quality services for seniors with blindness and other visual impairments by teaching the rehabilitation skills necessary for independent living in the consumer's home and community. Teacher assistants are peers, and as consumers of Aging Network services themselves, readily help those with blindness and other vision impairments access the Aging Network service structure.

Objective #3

A portion of grant money is used to provide adaptive aids and devices, orientation and mobility instruction, and transportation for older people with vision loss.

This money provides support services that increase the personal independence of people with blindness and other visual impairment. Three types of services are approved for purchase:

1. Orientation and mobility training services, if provided under prescription of DVR's rehabilitation teachers by certified, itinerant orientation and mobility specialists.

2. Low vision services, adaptive aids, and other devices that enhance independent living for older people with blindness or other visual impairment.

3. Transportation services to improve consumers' access to important local and state service programs that may enhance independent living.

Another positive facet of this project is its sponsorship of free vision health screening clinics that can detect glaucoma, diabetes, or other conditions which may lead to severe vision loss. The clinics target older people without access to ophthalmological care, and are held at rural senior citizen centers, community centers, and Native American tribal centers. Staff provide educational brochures, discuss eye conditions and rehabilitation resources, and make referrals as needed.

Why are these prevention activities so important? The U.S. Census Bureau states that 22 percent of all people over age 65 have some level of visual impairment which limits daily activities. The American Foundation for the Blind states that half of all people with blindness are over age 55; and the American Academy of Ophthalmology estimates that half of all geriatric blindness is preventable!

For more information, contact the Wisconsin Department of Health and Social Services, Division of Vocational Rehabilitation, Office for the Blind, 1 W. Wilson St., P.O. Box 7852, Madison, Wisconsin 53707; 608/267-3377.

INTERAGENCY NETWORKING

Brian Atwell, Coordinator (Presenter)

Services Narrative

LINK, Inc. is a private, not-for-profit independent living center servicing the 18 northwest counties of Kansas. LINK has a longstanding philosophy of working with community agencies and organizations to establish linkages with them and, as much as possible, to encourage the natural, generic service provider to make its services accessible and available to people with disabilities, rather than to see a "special" service provided.

LINK has been instrumental in the development of accessible public transportation in Ellis County, the largest (population 24,000) county in our service area. Currently the city of Hays, Ellis County, the Kansas Department of Transportation, Western Kansas Association on Concerns of the Disabled (WKACD), Developmental Services of NW Kansas (DSNWK), the Ellis County Council on Aging, Early Childhood Developmental Center, Inc., Ellis County United Way, Fort Hays State University, the Disabled Students Association, and the Hays Good Samaritan Center all participate in the cooperative, coordinated effort of providing accessible public transportation in Ellis County.

The purpose of the transportation program is to provide transportation to citizens of Ellis County. This program was driven (pun intended) by the needs of individuals who do not drive, as our community did not have any generally available transportation (no, not even a taxi). Because of this, people with disabilities and older people were involved from the beginning in the development and implementation of transportation services.

Ellis County, like many rural communities, had bits and pieces of funding and vehicles available. The Western Kansas Association on Concerns of the Disabled owned and operated a lift-equipped van it had acquired through Easter Seals and university money. This van was the forerunner of the accessible service. Developmental Services of NW Kansas, The Good Samaritan Center nursing home and the Early Childhood Developmental Center had all purchased vehicles for consumers through Section 16(b) and Section 18 funds provided by the Kansas Department of Transportation (KDOT). Some operating costs were provided as well. The city of Hays had a senior citizen's van with a lift, funded through the Older American Act, that was used to transport people to meal sites. For the most part each organization provided limited services to its specific group with no coordination between organizations.

The accessibility project was developed when all the providers and sources began to realize that services were not cost effective and were not even beginning to meet the needs of the citizens in our county. KDOT was concerned by the number of projects they were funding and looked to their largest recipient, DSNWK, to resolve the issue of too many vehicles and very little resulting service. Their intervention was key, for the potential of losing funding or control resulted in all groups willingly participating in a coordinating council for the purpose of organizing a single public transit system for our county.

Because it had the most vehicles, DSNWK agreed to assume the cost and responsibility of dispatching services. LINK worked with DSNWK staff to help them understand the need for accessible transportation, set up schedules that were responsive to consumer requests and establish an advisory council of service recipients to continue to guide the development of the transportation system.

Once KDOT had identified a coordinating entity, it required the existing projects to coordinate through DSNWK. Enough money was freed up to expand services and to provide dispatching for all the services. WKACD continued to assume responsibility for the matching funds for the van it had operated, and for the purchase of replacements, allowing a consumer-controlled group to continue to make the key decisions regarding accessible transportation in the county. LINK and WKACD supported DSNWK's applications for additional operating funds from the city and county as services were assumed there. Today the system is unified and provides the extensive services we have described above.

A key component was that all the people receiving funding were willing to add their resources to a single project for two basic reasons. First, we as rural people have always had a sense of "neighborliness," and we could see that fragmented services would never have the level of success that could be achieved by coordinated services. The second reason was that we were not afraid to use the bureaucracy of the mutual funding source to bring additional pressure to bear for a coordinated system. The results speak for themselves, and could be replicated in any similar community.

People of all disabilities are served by this program. Last year this service averaged more than of 2,000 rides per month. The past month was 2,883. While LINK cannot be sure of the number of individual riders, the number has steadily increased, delivering a significant, and still rising, impact of more than 34,000 rides a year.

Involvement of People With Disabilities

People with disabilities were involved with organizing and participating in the first coordinating council meeting where the structure of this program was mapped out. In addition, they continue to serve on the advisory council for the transportation service. All riders are given an annual opportunity to evaluate their satisfaction with the service.

Impact of Service

Before this program was initiated, nine community organizations provided sporadic transportation services to their own consumers during very limited hours and only within the Hays city limits. By combining resources and coordinating services from a central point, we have been able to provide service from 7 a.m. to 5:30 p.m. weekdays, with extended service until 11 p.m. two nights per week and 9 a.m. to 4 p.m. service on Sunday. Weekday transportation is available county-wide between and within the various communities. The expanded service is coordinated through central dispatching by the primary KDOT recipient. The other programs have either turned their vehicles over or are available to provide backup for the service.

Because fixed routes were only a partial solution (it is difficult to get to a route when the community is not fully accessible) the service is primarily demand/response. Fixed routes are operated for people who work or attend the university and need a set daily time for arriving at their destination and returning home. Of course other riders are permitted to join the service at any of the fixed route stops and ride to any of the others, but there is little demand for that.

What an impact these services have had on the lives of consumers! While we cannot yet afford seven-day, 24-hour service, the entire county is now accessible to people with disabilities through public transportation.

On an interesting note, the Kansas Department of Transportation has proposed House Bill 2971, a transit district formation bill, and indicates in its testimony supporting the bill that Kansas currently contracts with nearly 200 individual providers of transportation services statewide (there are 102 counties). KDOT plans to begin contracting with two regional transit districts this year. These two districts have been formed voluntarily and will serve as demonstration districts. The project described in this proposal is the rural district indicated here.

Resource Cost of the Service

The cost of the services absorbed by DSNWK that were not covered by other sources was considered to be appropriate, since coordination efforts allowed DSNWK to continue their services as well as expand to new areas. New costs were as follows:

SALARY	Total	Funded	Unfunded
Dispatcher	9,108	3,643	5,465
Coordinator (45%)	3,139	2,511	628
Coordinator (cont.)	6,986	6,986	0
(Coordinator is in two cost centers)			
TAXES & BENEFITS			
Dispatcher	1,138	455	683
Coordinator (45%)	953	762	191
Coordinator (cont.)	2,122	2,122	0
TRAVEL	358	286	27
COMMUNICATION			
(Coordinator grant)	184	147	37
Toll-free telephone line	150	0	150
Toll-free monthly charge	480	384	96
EQUIPMENT			
Repeater Station	2,844	0	2,844
Mobile Radios (4)	1,967	0	1,967
Computer, Modem, Software	711	0	711
3,557 x 20%			
Less DOT Reimbursement for Radio, Modem, Software		627	<627>
TOTAL	30,140	17,923	12,217

Networking

As stated above, LINK worked with nine organizations that all had some component of a transportation service. Some of the networking was voluntary. In some cases, the pressure brought to bear by the primary funding source was a key motivator.

Continuation and Replication

This service has been continuous since 1987 and continues to expand. We believe that many rural communities, like ours, have fractured transportation resources. Many times the different groups are reluctant to let go of their own little services in order to add to the pool of resources available in the community. However, if they could see how such cooperation has benefitted our community, replication is more likely. In addition, our model contains advisory committee and evaluation components, enhancing the service's accountability to its consumers.

Exemplary Nature of Service

As evidenced by the priorities selected for the Exemplary Practices applications, transportation is a key to independence for people with disabilities in rural areas as much as in urban ones. This project is unique in that it cost the independent living center, LINK, only our staff and consumer time to ensure the provision of sufficiently funded cooperative transportation.

The cost to the community agency that assumed the service has been minimal, with only $12,217 out-of-pocket expense during the set-up period. Any community that has splintered transportation resources can, by replicating our model, provide extended accessible transportation in their community.

Staff Transportation to Consumers

Two of our staff members do not drive; they use this service to meet with consumers when they need to go to a consumer's home. In our other service area we travel to the homes of consumers routinely. However, this component is not related to this application.

For more information contact LINK, Inc. (Living Independently in Northwest Kansas), 1310 Walnut, Hays, KS 67601; 913-625-6942 (Voice/TT).

THE COMMON THREADS

All networking should reflect the needs of the consumer and his or her family – personal empowerment gets consumers involved. Formal and informal partnerships have different aspects and strategies:

Informal agreements

A marketing approach can help an individual or organization plan what to do, whom to involve, and how best to develop a network. The individual and/or organization must first become highly visible in the community. **This means making frequent community contacts with providers of services to minority and low-income groups, employment agencies, county officials and other community leaders.** Community leaders should always be kept abreast of your activities; call them before anyone else. It's important to identify unlikely, but influential, community members and include them in your network. There are many people without titles or official positions who are respected and listened to by people in the community. Contribute articles for newsletters and local newspapers; these are frequently reprinted in other publications or copied and passed around; they lend professional credibility as well as exposure. Develop the habit of writing and sending frequent thank-you notes. **Build a community relationship by volunteering your time to other organizations and by investing in the local economy (shop locally).**

Provide a continuum of services; **identify gaps in service and use them as marketing tools as you develop services to fill those gaps.** Include local consumers in the network and encourage them to tell their own stories. **Define resources broadly to include nontraditional, nondisability-specific services and natural consumer supports in networks.** To solve transportation problems, invite as many agencies as possible to brainstorm possible solutions.

The key issue is knowing your community, both who to network with and how to go about it. Be prepared to redefine the local bar or restaurant as an "agency," if necessary. Language is important; avoid using "consumers," "clients," "patients," and the patronizing "our families" or "our children." The community must know who you are and what your organization hopes to achieve. **Develop a mission statement** and define your mission and objectives to the community; this can prevent or clarify any misconceptions. Your actions and practices must always reflect an awareness of local cultural issues.

Formal cooperative agreements

Restructure formal agreements annually. Networks are dynamic and need constant re-evaluation of their direction. Assign specific responsibilities to each of the partners. Obtain a hierarchy of signatures for compliance. Explore a variety of funding options. There are other possibilities beyond always looking to the state for matching funds. Consider all funding options, such as Education for Blind Students; state matching funds for Independent Living Centers; and foundation grants from corporations. **Develop collaborative relationships with all state agencies sharing common interests:**

- Contact them and establish a rapport. Share your stories of problems and successes. Identify any mutual needs and the mutual benefits of interagency cooperation. Get to know everyone in an agency; secretaries and receptionists can speed processes along and cut through red tape. **Establish the guidelines for your cooperative agreements. "Playing politics" and "turfism" hinder networking; find ways to eliminate them.** Networking should be a nonthreatening activity which doesn't create fear of job loss in agency staff.

- **Relationships must be reciprocal, with all sides profiting.** For example, you can make presentations to other groups and agencies; invite them to make presentations to your organization. If you make referrals to other agencies, they may reciprocate by making referrals to yours. Share your facility with other groups and contribute to their efforts. Share transportation, computer equipment and databases, inservice training and workshops.

- Agency networking uses limited budgets more effectively. Don't compete for limited funding; work together to make the funding pie bigger. Cooperation among agencies can cut through funding red tape.

- Cooperate to make state guidelines locally-flexible. Together you can streamline procedures, such as combined eligibility and application forms which can be used by multiple agencies.

- **Bring parents, churches, business advisory councils, city councils, school boards, special education transition teams, Chambers of Commerce, citizens' advocates, and tribal government representatives into the interagency network.**

In Summary

Have an attitude: be positive, patient, persistent, and passionate. Look before you leap into networking. Avoid incestuous systems that include the same people on every task force. Network with other networks. Build ongoing communication -- networks develop over a long period of time. "Feed" the network; inform and reinforce the group frequently and highlight its progress. Focus the group on its task, but remember partners must have equal footing; identify and relinquish your need for control.

Rural Strategies

In an early intervention program, the family and agency cooperated to create an Individualized Family Service Plan for the child and family. However, when a child graduated to public school, communication broke down and children frequently received inappropriate or inadequate services. The local independent living center joined parents in establishing a link with the local school to plan more effective educational services for children with disabilities.

> In **New Mexico**, a philosophical emphasis on people with disabilities "being cared for," as opposed to "taking care of themselves" resulted in many people living in nursing homes. An attendant care services legislation task force brought nursing home residents together with nurses, nursing home administrators, representatives of state agencies and others. The enforced communication is changing attitudes.
>
> An itinerant **New Mexico** service provider is aware of differing local cultures, religions and politics. He reads all available local newspapers, so he can talk to community members about

local elections (and network with local politicos). He changes clothes to suit the locale, attends local events, eats in local restaurants and takes pains to shop in local stores. In the most rural areas, his "office" is the post office, where people must stop for their mail.

As an alternative to formal support groups, an **Arizona** program arranges introductions between parents of young children with disabilities. Two parents or two families meet in a casual setting for lunch, a movie or a picnic in the park. Many are more comfortable with this method of establishing a family support network.

In **Wisconsin**, elders with visual disabilities receive in-store assistance with their shopping. The service provider talked to grocers, provided inservice training for store employees, and listed participating stores in a newspaper ad. Nonparticipating markets now call to volunteer their stores for the program.

In **Missouri**, independent living center employees recognize the long-term benefits of community volunteerism and sit on many nonprofit boards of directors, including several which aren't disability-related.

A **Missouri** ILC employee expressed his enthusiasm for a local baseball team to a state legislator. The legislator shares the employee's interest and, through their sports discussions, has become much more positive about disability-related legislation.

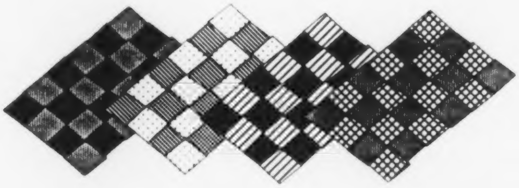
A **California** agency invites another agency to use its building for family/child assessments, for the YWCA to conduct parenting classes, and for early intervention specialists to conduct training.

A local rural radio station carries a weekly show on disability issues and problem-solving.

Sometimes, just pointing out a problem can result in a solution. A consumer called the local school board asking to be put on the school board meeting agenda to talk about handicapped parking at the schools. Her request for parking spaces was acted on immediately, without need to address the board. She had similar experiences when she asked for parking at a baseball field and the public library.

In **Georgia** a nonprofit service provider agency monthly sifts through the large amount of information it receives and makes up resource lists for independent living council members, advocacy groups and others. Recipients can choose which resources look useful and call for more information.

In **Maine**, a university psychiatric rehabilitation program worked with the Alliance for the Mentally Ill, consumers and their families to develop a supported housing project. Members of the Alliance are now involved in co-teaching some psychiatric rehabilitation classes.



TRAINING RESOURCEFULLY

One of the 1991 "Common Threads" stated, **"Not only designated 'trainers' provide training in rural areas; most people involved with disabilities train consumers, family members, staff, related professionals, or community members at some time"** (Common Threads Proceedings, 1991). In rural areas, everyone, including many consumers, does training of some sort -- it's just common sense. Few, however, consider themselves to be "*Trainers.*" **Rural training may involve helping someone acquire skills, proficiency, and new abilities. It may be helping someone access the information and resources they need. Even if it's not formally identified as "teaching" or "training," the rule of thumb is that, if you are not actually doing an activity for a person, you are probably training that person to do it for him or herself.** These activities are often taken for granted, so the informal trainer may not think about how to share training strategies, or how to train more effectively.

In Common Threads '92, we explore what rural "training" means in a broad sense. Participants identify important rural training issues and some of the resourceful ways they have responded to formal and informal training challenges. As with Common Threads '91, shared training, empowerment, sticking to the basics, and planning for ongoing training opportunities are integral to each success story.

GENERAL EDUCATOR GRADUATE PERSONNEL PREPARATION: KANSAS RURAL FULL INCLUSION EDUCATION MODEL

Patti C. Campbell, Associate Professor (Presenter)
Charles R. Campbell, Senior Scientist

This paper describes a model program under development by faculty of the Pittsburg State University Department of Special Education and Administrative Studies and the University of Kansas Department of Special Education. The program is designed to prepare preservice general educators from rural Kansas to work with children and youth with disabilities and their families in neighborhood schools that support a full inclusion philosophy. The paper will address three themes:

1. Educational restructuring and the role of general educators in serving students with disabilities in fully inclusive educational settings in rural Kansas schools;

2. the development, field-test and validation, evaluation and implementation of a next-generation instructional technology model for use in graduate personnel preparation; and

3. the dissemination of instruction through advanced distance-learning instructional delivery technology for rural settings.

Educational Restructuring in Kansas

As a response to a growing national trend toward school restructuring, the Kansas State Board of Education's Quality Performance Accreditation (QPA) System addresses school improvement, accountability and individual student performance at the building level. The plan is intended to be flexible and subject to change based upon input from teachers, administrators, boards of education and parents selected from the first 50 pilot districts.

The QPA system focuses on the skills, attitudes, and disciplines that students will need to live, learn and work in a global society. These skills are addressed through an integrated, comprehensive curriculum with emphasis on creative thinking, problem solving, and communication. Basic skills also are addressed through the integrated curriculum. The QPA requires local schools and districts to identify the basic skills that are to be mastered and to report the results at the local level. It is expected that Kansas districts and schools will identify and work toward locally determined standards and indicators, as needed, to support a comprehensive school program.

As in many current restructuring efforts, there was statewide concern that the QPA did not specifically address the needs of students with disabilities. To address this common concern the following recommendation was put forward by a planning committee from the University of Kansas, School of Education (1991):

> A subset of at least ten representative districts from among the fifty districts volunteering to participate in the first-year implementation of the Kansas Quality Performance Accreditation plan should be invited to specifically address the identification of outcomes and indicators for exceptional students (p. 56).

As a result of this recommendation, eleven districts volunteered and were designated to address the specific needs of students with disabilities in inclusive settings. These eleven sites are distributed throughout the state of Kansas and are the first priority target of the instructional training program addressed by this paper.

Instructional Program Development

Professionals have witnessed the development of procedures and practices, both instructional and philosophical in nature, that may be said to represent the current "state-of-the-art" of fully inclusive education for students with disabilities. The knowledge that strategies have been developed and demonstrated, and the sure reality that students with disabilities are still not being fully included in general education settings in neighborhood schools support the importance of an effort to reduce the gap between the "state-of-knowledge" and the "state-of-practice." The results of a preliminary analysis of the literature regarding specific skills that have been identified as "exemplary practices" in inclusive education are reflected in the four thematic competency areas outlined below.

A series of four competency based modules are under development as part of the instructional program development phase. These instructional modules place emphasis on developing teacher competencies that promote collaborative planning among general and special education team members that includes coordination through mutual adaptation of instruction and interdependent communication through school improvement planning. The instructional modules are designed to be offered as part of a master's degree program, an area of specialization or as an in-service program for CEUs.

Collaborative teaming: Skills for planning and implementing communication with small groups. This competency area addresses training skills necessary for teaching teams to solve problems associated with the inclusion of a student with disabilities in the general education environment. Examination of the literature on team and cooperative teaching, collaborative consultation, adult collaboration and group theory was particularly useful in identifying specific skills necessary for effective teams. Skills necessary for building interdependence of teams, group functioning and techniques establishing individual and group relationships are included. Content focuses on the development of leadership skills that stress giving and receiving positive and negative feedback and conflict resolution strategies.

Curriculum adaptation: Planning and adaptation of skills that promote inclusion. This competency area focuses on skills necessary to integrate the IEP goals and objectives of students with disabilities into the general education curriculum, management skills and an instructional delivery framework that can be utilized in the general education setting. This competency area addresses instructional content from both general and special education that has been used successfully by fully inclusive schools to promote the transition and maintenance of students with disabilities in the general education environment.

Outcome-based instructional design: Skills for adapting instruction to clearly define student outcomes. This competency area addresses training in instructional planning and delivery skills that have been successful in fully inclusive schools. The instructional materials identify characteristics of "outcome-based education planning" that promote the transition and maintenance in general education classrooms of students with disabilities. The competency area also addresses instructional content related to direct and systematic instruction, data-based teacher decision making, and systematic evaluation of educational services.

School improvement planning: Skills for Implementing Full Inclusion Education. This competency focuses on the skills necessary for general and special educators to develop, implement, and evaluate the full inclusion program for the transition and maintenance of students with disabilities in their neighborhood school. Outcome-based education planning skills are utilized. In addition, competencies for developing organizational skills of time management, scheduling and data management are emphasized.

The instructional program incorporates exemplary practices for training of general education teachers to include students with disabilities. The training is interdisciplinary in nature and is based on competency and performance. Field experience is extensive and rigorous, designed to create fully inclusive school and community settings. The philosophical underpinning of the program is that individuals with disabilities are students with the right to a quality education within their local public schools. The program is designed to prepare personnel who can fulfill the following terminal competency.

> Trainees will develop, implement and evaluate a full inclusion and outcome-based education service delivery model for students with disabilities within each student's own home school which optimizes inclusion, participation and social interaction in current and future educational, vocational and other community environments.

Instructional Delivery Approach

In Kansas rural administrative units account for 52 percent of the total Kansas student population (\ abel and Costello, 1991). In general, rural districts have more difficulty grouping students due to smaller numbers and geographical distribution of students with disabilities. This difficulty makes rural districts prime candidates for increased inclusion of students with disabilities in regular education settings. Planning and implementing full inclusion programming is a natural approach to meeting the needs of these students in rural districts. Of the eleven QPA districts targeted for this project, five are located in rural areas of the state and do not have easy access to campus-based university training. Meeting the training needs of personnel in these districts requires the use of innovative instructional delivery strategies. Reaching rural Kansas teachers will be accomplished through the use of interactive telecommunication technology now under development statewide.

Providing training in rural settings meets an important need for functional demonstration of this advanced instructional delivery approach. Graduate students from all regions of the state of Kansas will have access to the program through the use of instruction adapted for use through distance learning technology. This developing technology is a critical part of bringing new instructional skills to rural educators across the state of Kansas. Many of the targeted personnel live at distances too great to come on a regular basis to campus-based course offerings. For this reason the field-based instruction is offered through a non-traditional interactive telecommunication delivery system being developed in Kansas.

Through the collaboration of the two universities nearly all of the state can be reached by interactive telecommunication transmission. Classrooms at each university site provide two-way interactive television. Thus the instructor at the university teaching site and participants at the distance learning site can see each other and communicate as if they were in the same classroom. The two-way interactive television system uses a CODEC (code/decode) device to compress and decompress the signal at either end of a telephone line and a video monitor at each site. These systems are compact and highly mobile. The quality of transmission is rapidly reaching full motion quality while using fewer telephone lines. Fewer telephone lines means lower cost for transmission of high quality video and audio. Kansas is implementing a statewide effort to utilize a compressed video system through local full motion, fiber optic based regional loops to bring economical, long distance instruction and assistance to special as well as regular education students and personnel.

Summary

We must expand our ability to implement models of full inclusion, although often controversial, at the local education agency level. The implementation of fully inclusive educational practices ultimately resides with the local educator. Regular classroom teachers as well as traditional special education teachers must develop new skills to effectively collaborate with each other and with parents. Adequate training technologies must be available to assist them.

The approach outlined in this paper exemplifies the recognition of these demands and the application of developing training technologies that are required. The instructional materials and strategies described in this paper can help to meet the immediate needs of local educators for training in the implementation of an inclusive education program. Finally, this approach also represents the blending of instructional development and the application of instructional delivery technology to meet the unique needs of rural educators in a cost-effective and efficient manner.

For more information contact the Schiefelbusch Institute for Life Span Studies, Kansas University Affiliated Program at Parsons, 2601 Gabriel, University of Kansas, Parsons, KS 67357; 316/421-6550, ext. 1859.

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CORVALLIS SCHOOL INCLUSION PROJECT

Jo Jakupcak, Resource Teacher (Presenter)
Richard Rushton, Science Teacher

Teach Me To...Teach *Me*, Too! is an experimental program meeting the needs of secondary students with disabilities in the regular classroom setting, using a regular educational curriculum. The program began in September, 1991, in Corvallis, Montana, as part of a Toyota Corporation grant awarded through the National Science Teachers Association. Corvallis teachers Richard Rushton (science) and Jo Jakupcak (special education) wrote the program in response to Corvallis Public School System's adoption of an inclusion policy that educates all students, regardless of diversity of need, in the regular classroom. This philosophical shift required new service delivery models, coupled with new methods to enhance learning for all students.

Each student is evaluated and placed in regular classes. Unique educational needs, either of students with gifted abilities or educational disabilities, are met in the regular classroom through: (a) Consultative Services; (b) Team Teaching; and (c) Tutorial Services.

Team Teaching provides direct classroom support to the students and meets the needs of all class members, with or without identified special learning needs. Teach Me To...Teach Me, Too!, emphasizes every student's right to be taught at his or her highest level of understanding; it allows the regular classroom teacher and the special educator to work effectively and efficiently as teammates. It capitalizes on each teacher's special knowledge and abilities, and makes each lesson more relevant to the students. The model has four components: (a) Pre-teach; (b) Teach; (c) Post-teach; (d) Study skills class presentations.

Pre-teach

Key concepts are pre-taught to those students identified through the Child Study Team Process as having special learning needs, due to learning disabilities, developmental delays, emotional disturbances, or an attention deficit disorder. During a regularly-scheduled lab session, these students and any other classmates earning a "C" or lower, may attend a preview lesson. This weekly lesson teaches the same concept to be taught later in the week during the regular class time. It is, however, taught with different materials so that students aren't merely memorizing information, but generalizing from one set of learned materials to another. Each student has the opportunity to practice higher level knowledge application and analysis skills.

Teach

Pre-taught students attending regular class have prior knowledge of the lesson's content. The teacher addresses the entire class, often uses cooperative learning groups in the lab setting, and encourages peer tutoring and positive interdependence. The pre-taught students are often confident enough to serve as group leaders, demonstrating hands-on techniques to their classmates.

Post-teach

Students with special educational needs review key concepts before taking a test, using an array of memory enhancement techniques to study the material. They take the same test, in the regular classroom, and usually at the same time as their classmates do. Occasionally, test questions may be read aloud to compensate for reading skill levels that may be from two to six years below grade level.

Study Skill Class Presentations

In the Teach Me model, the regular educator teaches course content, such as science, social studies, or literature. The special educator presents a weekly lesson on how to learn, demonstrating note-taking skills, test-taking strategies or time management tools. Students may be tested for modality preference and most-effective learning styles. Students learn about the thought process and how to learn metacognitively. Occasionally, the special educator simply demonstrates good note-taking skills on the overhead projector or the chalkboard as the content teacher lectures. The content teacher urges students to apply newly learned study skills to specific course materials and tasks.

Student Evaluation

Teach Me activities are evaluated in several ways. Each class member predicts his or her own grades and sets personal educational goals. Each week the students spend five minutes writing a three-part journal entry. In a sentence or two, they summarize major concepts presented in class that week, predict what will be taught next, and express one fear or concern about their own educational progress. The two teachers take turns responding to these journal entries. They also share the task of checking notebooks for adherence to a sound note-taking system. On quarter and semester tests, the special education teacher provides a one-page study skills evaluation for each student and this score is factored into the student's total score for the class. The teaching team reviews all class members' quarterly grades, and urges students with low grades to attend the special lab sessions for informal small group attention. Attendance for students without disabilities is voluntary; students with disabilities must attend.

Program Evaluation

The first year of the Teach Me To...Teach Me, Too! program at Corvallis was very gratifying to teachers, administrators, students and parents. Ten students with special needs participated in this supported education model, and all passed the course with a grade of "C" or better. They each met every criterion for the class – they wrote reports, performed science lab experiments, and passed tests on the content presented to the whole class. Their grades were not altered in any way, nor were their performance expectations adjusted to allow for their disabilities. They achieved a mastery level of learning. In addition, 80 percent of the entire class earned grades that were higher than either their self-predicted grades or their previous year's science grades. The remaining 20 percent were students with poor school attendance records, for various reasons.

The personal stories are dramatic. One young student with severe social problems was a "victim," frequently stuffed into lockers by other students. He spit at other students from the school bus windows, and spoke only in monosyllables. In the Teach Me model, he was assigned as the science teacher's permanent lab assistant. Within a month, he learned to operate a complex set of computer programs, and became a self-assured young man who now teaches others how to run the new computer. While his written language scores on standardized tests remain well below grade level, his science scores are in the 90th percentile and he wants to bring other skill areas up enough to be accepted for college.

Four of the ten students had histories of long-term placement in self-contained special education classrooms. One of these students prepared an elaborate science fair display comparing Soviet rockets with American rockets. The research and writing was a real challenge for him; he reads and writes at a third grade level, but thinks at a ninth grade level. Another student in this group explained her own learning style and study methods to a student teacher who was uncertain how to teach students with learning differences within the regular classroom.

Visiting program evaluators from the National Science Teacher's Association assumed two of the students with special needs were class leaders because of those students' pertinent questions and enthusiastic participation in classroom discussions. Three of the students show serious interest in pursuing science at some level as careers. Teachers in other content areas noticed improved study skills in many of the 108 students who learned these skills in the regular science classroom. Teach Me's improvements in study skills, student/teacher communication skills, and test-taking skills were a school-wide bonus.

Conclusions

The National Science Teacher's Association awarded a second-year continuation grant, encouraging Corvallis to expand the program to include other science classes, to examine data and to write and disseminate the results of this initial year of successful educational experimentation. The cost of the program was the science teacher's investment in a one-hour weekly extra lab session, and the special education teacher's one-hour weekly study skills sessions for each of four physical and earth science class sections. The grant award provides Corvallis with an extra computer and software, plus an array of hands-on lab kits; but it is really the concepts of pre-teach, teach, and post-teach, coupled with high expectations for each student that are the core of this program's success.

For more information contact Corvallis Public Schools, Attention: Jakupcak/Rushton, Box 700, Corvallis, MT 59828; 406/961-3201.

USING MASTER TRAINERS TO TRAIN DIRECT SERVICE SUPPORTED EMPLOYMENT STAFF

David Wilcox, Project Coordinator (Presenter)
Corey Knox, Family Therapist (Presenter)

Supported employment is an activity which meets the employment needs of people with developmental disabilities and chronic mental illness. Effective supported employment requires trained staff, but there is a nationwide deficit (Inge, Barcus, & Everson 1988) and the need for trained personnel is growing rapidly (Renzaglia & Everson 1990). Additionally, Rusch et al. (1989) found a high staff turnover rate, partially due to inadequate direct service skills.

In Alaska, 6,871 individuals who could benefit from supported employment services have been identified by the Governor's Council for the Handicapped and Gifted, the Division of Mental Health and Developmental Disabilities, and the National Head Injury Foundation (Alaska Division of Vocational Rehabilitation State Plan, 1987). The population needing supported employment services is spread over the entire state, with up to half living in rural areas. There is a sizable need for trained, qualified, community-based direct service staff, which will be exacerbated as a service delivery system is developed for individuals with severe mental illness who need supported employment services.

Recent surveys suggest the number of Alaskan supported employment service providers is inadequate to handle the demand for services (Ward & Knox 1991). Unfortunately, agencies also reported a high rate of direct line staff turnover.

Alaska has an enormous land area with both urban and rural populations, as well as several Alaskan native groups. Geographical and cultural factors necessitate innovative training and service delivery strategies. Needs assessments showed that service providers were not satisfied with the training available to them. Training did not address the unique problems of rural supported employment, different approaches to job analysis, the need for ongoing support, etc., and created major problems for providers whose staff had been trained by different organizations. Alaskan service providers wanted input into training curricula so their personnel would use consistent approaches. Many Alaskan service providers train only a few staff members, making traditional university courses impractical. Existing curricula, according to Fairweather and Fergus (1987), were designed for small group instruction and are not practical for individual use. Alaskans needed a training system that provides individual training, regardless of time or place. Vast differences between urban, rural, and remote areas in the state call for innovative, flexible, broad-based training strategies.

The University of Alaska Anchorage Center for Human Development received a two year grant from the U.S Department of Education, Rehabilitation Services Administration to address this challenge. The goal was to develop a curriculum, train direct service delivery staff using a Master Trainer in supported employment approach, and evaluate the effectiveness of the Master Trainer method.

To ensure that the unique training needs of Alaska were met, an Advisory Board consulted on curriculum materials development. Advisory Board members represented urban, rural, and remote sites from around the state and diverse types of agencies and service providers. The Advisory Board provided valuable information and feedback on training topics, training methods, and Alaskan regional and cultural needs.

Advisory board input and a literature review identified eleven significant topic areas. These topic areas were then developed into eleven individual modules, each containing: reading summaries, readings from professional literature, exercises, and post tests. Modules were designed for self-paced independent study.

A pilot training program provided valuable feedback for revision of training materials. Training sessions lasted two weeks. During the first week, Master Trainers were instructed in adult learning, consultation, and the curriculum materials. During the second week, the Master Trainer trained pre-service staff in the curriculum, which is based on the needs of the adult learner. Fifteen Master Trainers, reflecting a large cross-section of agencies throughout the state, and 30 pre-service staff were trained in six training sessions.

The Master Trainer approach to curriculum development and training responds to the problems expressed by service providers; it meets Alaska's diverse needs. The entire curriculum includes video instruction (to enable Master Trainers to train new staff at the agency's and employees' convenience), and "train the trainer" manuals for Master Trainer instruction. At the completion of the grant, revised curriculum materials will be used by the University of Alaska, Anchorage to continue both pre-service training and Master Trainer workshops. The university is also using the curriculum in a long-distance audio teleconference course.

This project is currently being evaluated. Early results show an increased number of staff skilled in providing supported employment services. The project may have implications for continued training in Alaska and may meet training needs in other rural and urban areas and culturally diverse populations.

For more information contact the University of Alaska Anchorage, Center for Human Development: University Affiliated Program on Developmental Disabilities, 2330 Nichols Street, Anchorage, AK 99508; 907/272-8270.

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HEALTH PROMOTION

Bill Botten, Program Director (Presenter)

It has been identified that the age group of 15-24 is at the greatest risk of receiving a brain or a spinal cord injury, especially in rural communities. So our school-based program was based on a national model, called Think First, that was developed at the University of Missouri in Columbia. The program uses a medical model that tries to show three things: that these issues are relevant to the audiences to which we speak; that they are very serious issues; and that it is possible to prevent these injuries through some risk management.

Our program discusses issues such as alcohol and drug usage in risky activities, such as diving, checking the depth of the water. Other issues include seat belt usage, child passenger safety, helmet usage and pedestrian safety through bicycle helmets. The program lasts about one hour. We speak to groups ranging from a small class to thousands of people.

It is a multi-media event. We use a series of slides to discuss the statistics and the relevancy to these young people; we show the anatomy and physiology of the human spinal cord and brain, the central nervous system. We use an award-winning film called "Harm's Way." It keeps their attention and gives them a better opportunity to learn from and hear about different types of injury situations from the people who have been injured, young people just like those in the audience.

I discuss my spinal cord injury and then we bring someone who has a brain injury to actually give testimony about how they received their injury and how could it have been prevented and what their life has been like since the injury. I think the program does a very good job of showing that for some people that do sustain these types of injuries and disabilities there is an opportunity to become an active part of society and that people with disabilities still have the same wants and dreams and desires that anyone has.

So there is a kind of hidden agenda -- to show people with disabilities in a positive light. We come to a small town where I driving with hand controls and we bring all of the things we need to set up the program and a young person with a head injury, and we give them an opportunity to see that a lot can be accomplished from a wheelchair, that you can still drive a vehicle and still live independently. However, I stress again that it is not for everyone; a large percentage of these injuries do not allow the individuals that sustain these types of disabilities the opportunity to live independently or to drive a vehicle again or to get an education. The seriousness of these injuries is presented throughout the program.

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Our program doesn't use blood and guts; it tries to show risk management and the consequences of not using risk management behaviors. We try to emphasize that by taking the proper steps you can greatly reduce your risk of injury. I think that we keep their attention by not preaching to them or lecturing them, but just showing them ways that they can do simple things in their lives to reduce their chances of injury. Rather than glorifying the injury, we give them tools to work with. I think it works.

We conduct anywhere from 80 to 100 educational presentations per year for young people between the ages of 15 and 24. We also make about 30 promotional presentations per year, encouraging PTAs or other local groups to urge their school administrators to get our programs into their community or district. This past year we had just over 20,000 attendees.

We have done a number of different video things, too. We did a 15 minute videotape on a cable channel here in Kansas City, a presentation that incorporated a number of our slides and overheads.

Our program is for private and public schools, primarily junior and senior high schools. We have a very difficult time getting into colleges, but this year we were at Kansas State and Emporia State. The majority of our presentations are in rural communities.

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We get most of our funding from the Department of Transportation and the Office of Traffic Safety here in Kansas. They awarded us a grant for 1988-1991 that got us started. All of the other funding has come through Farm Bureau Insurance, Cosmopolitan Clubs, other grants that have been written through foundations and in-kind donations. A lot of the equipment that we own has been donated through private agencies. We also have a fund-raising golf tournament every May. The association also has an annual fund-raiser called the Amy Thompson Run to Daylight and a percentage of that always goes towards prevention.

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We are working to incorporate this risk management education into the state's schools. We participate in a number of different conferences and health fairs in a number of different school districts each year. One that comes to mind is the Arkansas City Youth Awareness Conference. In years past, we have just been one of the workshops at that conference, but in the past two years we have been the keynote presentation that the whole school comes to first in the morning.

We really haven't worked through the Department of Education or the Kansas State School Board to try to implement this into the regular school curriculum, but I would love to see my kids be required to take a course.

I do a lot of presentations during the day to schools and a lot of them at night to PTAs and the parents are so glad to get this information. Sometimes the only way that I can get into schools is to have the PTA see the program and continually bombard their administration that they need this program there. I can't tell you how many schools I have gotten into because the PTA has requested it.

For more information, contact the Head Injury Association of Greater Kansas City, 9401 Nall, Suite 100, Shawnee Mission, KS 66207; 913/648-4772, 913/648-6669 FAX.

Training Resourcefully

THE COMMON THREADS

Address stereotyping and discrimination in the community first. For example, vocational training is useless if community employers still will not consider hiring people with disabilities for jobs locally.

Training must be:

- Eclectic. Train the consumer and everyone else in the consumer's environment (parents and other family members, employers, co-workers, friends). Make training consumer-driven. If training is not working, don't blame the trainee. Ask, "What can we do differently? How? When?" Training should be "top down, bottom up." Combine learning across levels. Train several groups at one time: parents, consumers, service providers, etc. **Consumers are effective advocates in awareness training; they have a vested interest in seeing discrimination eliminated. Community awareness training should focus on mutually-beneficial relationships between people with disabilities and other members of the community.** Train community leaders and community residents in a variety of locations (local bars, county fair, etc.). On reservations and other tribal lands, information-sharing is particularly important. If the reservation holds pow-wows, ask if providing an information table or booth is appropriate (be aware, however, that pow-wows are often religious observations where such activity may not be appropriate). Training is networking.

- **Hands-on**. Individuals need time to practice newly-learned skills. University-level training must unite theory with practice.

- **Customized. Learn what your group's/individual's needs and priorities are before beginning training; don't make assumptions about what their needs might be.** Offer options in subject matter, style of presentation, format of materials, and location of training. De-emphasize programmatic training objectives; try to discover what trainees hope to come away with from the session. Use the skills of participants and get them actively involved in the process. Emphasize local control and inclusion. Think on your feet: "What's important to these people?"

- Accessible. Buildings and formats must be accessible and training must adapt to local cultural needs. Long-distance education can be effective in rural areas.

- **Ongoing. Follow-up activities and ongoing support are necessary. Provide information and resources as the need arises. This is a long-term commitment.** Be patient, persistent and reliable. If at all possible, never cancel a meeting or a training session; people are depending on you and may have gone to great trouble to be able to attend. Cancellations destroy trust.

- **Consumer-involved. Consumers and their families can effectively train other consumers, other families, staff and community members.**

- Spontaneous. Some of the best training occurs spontaneously, outside the classroom. An informal one-to-one style is important in rural areas. Support groups needn't be strictly disability-related; members can share all types of information. In all situations, offer food to training participants. Find the common bonds of group members and a common language understandable to all.

- Shared. Form an interagency pool or "cadre" of trainers; there are more commonalities than differences across agencies. Each agency can contribute to the expense of maintaining the cadre and the trainers would train across fields. This reduces duplication of effort and promotes standardized training. Discover local "pockets of excellence" and disseminate their materials through your statewide network. Rural expertise is sometimes hard to find. Research and training centers could develop lists of national expertise and disseminate them. A national training clearinghouse could link trainers with areas of need. Conduct training for another agency and ask them to train your group. Shared training is a cost-effective arena for networking.

- Funded. Maintain training as a budget priority.

Rural Strategies

An **Indiana** program takes its wheelchair obstacle course to fairs and other events. Employees pass out information and accompany children in negotiating the course, emphasizing that a town's barriers to accessibility can thwart even the most accomplished farmer with a disability. The children often relay this information to their parents.

A disability agency provided training on the ADA to a Retired Senior Volunteers Program, then did site and accessibility evaluations for RSVP. RSVP has asked for more information on the ADA.

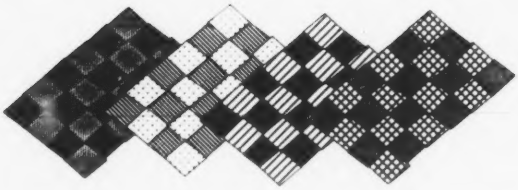
In **Washington**, employees go to a university for a week's training, then return home for a week to practice their new skills. Then they return to the university for follow-up activities. The goal is to have employees capable of training other staff, both in-house and in various other organizations. Providing training for other agencies fosters good relationships.

In **Oregon**, Vision Northwest (see 1991 Common Threads Proceedings) has organized an extensive network of peer supports for people with visual disabilities. This organization helps people work through their loss and grief and helps them learn self-advocacy, self-sufficiency and independence.

A **Wisconsin** program refers to its training sessions by the less anxiety-producing term, "sharing sessions."

A formal training class for people with traumatic brain injury had little success in teaching members to use notebooks for remembering daily tasks. However, when class members saw the technique used by their informal support group colleagues, many followed suit. The same thing happened in a recreation program. Formal classrooms may be too intimidating and the trainer-trainee relationship too evaluative for many people.

A campus chaplain in **Montana** designed a Ministry of Friendship in which ten college students were trained in weekly group and individual sessions. They became a very viable, active ministry to other students.



CULTIVATING CAREERS

The dictionary defines "cultivate" as to "apply oneself to improving or developing" and "career" as "one's advancement through life, especially in a profession" (The Concise Oxford Dictionary, 1991).

People with disabilities want to change how we think about employment, jobs, and vocational rehabilitation. Proposed changes in the Rehabilitation Act's reauthorization this year include emphasis on career issues. "Careers" have been generally discussed in the disability business, but the system is slow to move from emphasis on job placement to emphasis on career cultivation. Getting a job has long been the criterion used for successful rehabilitation closures. However, rather than look at employment as the goal, we should be looking at career development as the means of achieving independent living.

Those not involved in the employment field today may wonder where they fit into all this. It may be easier to see one's role as **promoting growth in an occupation followed as one's life work.** Small children with disabilities don't aspire to jobs that people think they could never do; one's life's work doesn't end at retirement.

The Common Threads share working strategies and do some future planning: what do participants want to see happen? What ideas do participants have about ways to reach those goals? Developing careers in rural areas has often required extraordinarily creativity. The disability world is changing, and rural programs can be at the forefront of the changes.

RURAL ISSUES IN REHABILITATION SERVICE DELIVERY: A GOODWILL INDUSTRIES OF AMERICA STUDY

Jeffrey C. Foley, Projects With Industry Coordinator (Presenter)
Carmen O. Larsen, Staff Researcher

Rural America offers a unique challenge in vocational rehabilitation service delivery. Because urban models often do not address issues that are specific to rural populations, new models specifically suited to a rural environment need to be developed and refined. This study, presented here in abbreviated form, attempts to isolate issues that might impact the outcome of rehabilitation programs when implemented in rural areas.

Background

Rehabilitation professionals working in rural areas customize service delivery models to suit their environment and often find themselves struggling with barriers that are not clearly addressed, if at all, in models typically developed based on urban factors and circumstances. Urban centers, with their larger client base, have been the focus of attention in addressing rehabilitation issues. Consequently, over the course of time, successful program models have evolved based on the profiles of urban communities.

Projects With Industry programs, for example, have proven very effective in urban and suburban areas. The programs are based on two principal components: providing skills training and placement in competitive positions at completion, and making use of a Business Advisory Committee (BAC) for guidance, feedback and, possibly, as a source of potential job opportunities. The BAC is an independent group that provides advice and counsel to the rehabilitation facility regarding employment issues which impact the vocational training program(s) provided by that facility. While programs such as these have been adopted by rural rehabilitation centers with some measure of success, they do not take into account rural-specific issues that can present significant barriers to improved program outcomes. Some of these issues may include the selection process for BAC participants, the types of rehabilitation programs implemented and community specific considerations such as access to transportation, social attitudes and family support.

The Goodwill Survey

Goodwill Industries was thought to provide a valuable platform for the study of rural versus non-rural issues in rehabilitation because of its structure (nationally, it is comprised of 173 local organizations) and its experience in rehabilitation service delivery (Goodwill Industries has been providing rehabilitation services to rural communities as well as non-rural communities since 1902).

Of the 173 Goodwills surveyed nationwide, 78 organizations responded. Overall, the response breakdown is as follows:

- Roughly 50 percent of Goodwills responded;
- 13 Goodwills, 17 percent of the respondents, characterized themselves as 100 percent rural;
- 22 Goodwills, 28 percent of the respondents, described themselves as completely non-rural; and

- the remaining 43 organizations represent a mix of rural and non-rural components.

Goodwill Study Summary

In summary, the Goodwill study indicates the following framework for understanding the dynamics of rural rehabilitation:

- There is great diversity in economic activity across rural America. While extractive industries such as farming remain an important factor and manufacturing plays a critical role in many rural areas, retail and service jobs dominate the non-farm employment in rural communities.

- Small and medium-sized businesses are the primary mode in rural areas.

- Jobs Seeking Skills training and Sheltered Employment programs are more difficult to fund relative to other programs in rural locations.

- People with mental and learning disabilities and economic dislocation are perceived as the categories of greatest need in rural areas, superseding physical impairment types of disability. In terms of clients actually served, rural rehabilitation programs are more focused on physical and mental disabilities than programs in urban areas.

- Job skills training, job coaching and job seeking skills training programs are less available in rural districts, perhaps in part as a result of difficulty in funding.

- Sheltered employment and work adjustment training are the dominant approaches used for job preparation in rural locations.

- Twenty-five percent of the Goodwills responding that claimed a rural component utilize a PWI or similar program in their rural area. PWIs are more prevalent in exclusively rural locales. PWI programs in rural areas demonstrate effectiveness in generating placements, but do not match the success rates found in urban environments.

- Transportation obstacles and funding are identified as the major problems perceived in the operation of rehabilitation programs in rural communities.

A Rural Service Delivery Model

As a result of the Goodwill survey a Rural Service Delivery Model was proposed. The proposed service delivery model is a Projects With Industry (PWI) model geared especially to the needs of rural clients. It utilizes techniques proven successful through the Goodwill experience.

Healy and Porter (1981) state that the career development process is crucial for working in rural communities. Sarkees (1990) asserts that this process should be undertaken as a coordinated effort involving the training program, home and the community.

The proposed approach emphasizes the participation of home, community, and business as essential partners in the effort of preparing and placing people with disabilities from rural communities into viable career paths.

The service model has six principal interrelated characteristics:

- Case Management
- Rural Marketing
- Career Development Program
- Business Advisory Council
- Community Participation
- Family Involvement

Case Management

The counselor/case manager receives the client for service, helps him/her develop the Individual Written Rehabilitation Plan (IWRP) and provides or refers the client for appropriate services to fulfill the plan -- guiding and counseling the client through the process to integrate the various services.

Rural Marketing

The marketer's job is twofold:

1. To market the rehabilitation center services to people with disabilities in the rural areas; and

2. to develop the employability potential of clients served by enlisting the cooperation of family, potential employers and community.

Career Development Program

The career development process is a self-directed assessment, planning and educational program. The counselor acts as facilitator to guide the participant through the acquisition of information, understanding, knowledge and skills that a client needs to establish, develop and plan for short- and long-range vocational goals.

The process involves 12 components: self awareness, career and personal assessment, career awareness, career exploration, career decision making and career planning, skills training, job seeking skills, job readiness training, placement services, career preparation and follow-up services.

Business Advisory Council

The proposed service model is a system that must include the direct involvement of the local business community, employers, and potential employers with the rehabilitation service center. The Business Advisory Council is the vehicle for such active participation. Utilization of county-wide Business Advisory Councils provides a genuine industry/rehabilitation partnership in which the rehabilitation service providers and the employer assume shared responsibility for integrating qualified people with disabilities into the mainstream of the world of work.

Community Participation

A critical component of this proposed rural service delivery model is community participation. A community advisory council will assist the project in identifying possible clients and obtaining services to assist in developing the employability of clients (transportation, child care assistance, etc.).

This group is made up primarily of social service providers (state vocational rehabilitation, JTPA, mental health, welfare services, school administration, etc.). Recognized community leaders must be identified and invited to participate in the community advisory council. Members of the council should be included in all stages of model implementation in order for the service delivery program to gain acceptance in the rural environment.

Family Involvement

Research has shown that parents are the single most important influence in the career-planning and decision-making process of their children (Drier, 1987). Families in rural areas tend to be close-knit and involved in each other's plans and undertakings. Thus the family has a richness of informal contacts that can help the family member with a disability access needed services or locate job openings.

From Research to Practice (Implementing the Model)

Goodwill Industries of America received a Projects With Industry demonstration grant from the Department of Education, Rehabilitation Services Administration, to implement the Rural Service Delivery Model outlined above on October 1, 1991. The grant is a five-year continuation grant, and four Goodwills are being funded by GIA to implement the model. Those four Goodwills are located in Colorado Springs, Colo., Flagstaff, Ariz., Knoxville, Tenn., and, Reading, Pa. The Goodwill study now moves from theory to practice.

For more information contact Goodwill Industries of America, Inc., 9200 Wisconsin Avenue, Bethesda, MD 20814-3896; 301/530-6500.

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LOCAL JOB BANK

John J. Niederman, President (Presenter)
Jennifer J. Mason, Workforce Service Director

Pathfinder Services, Inc. is a private, not-for-profit rehabilitation agency in Huntington County, Indiana, a rural county with a population of 35,000. Pathfinder has provided employment services for people with disabilities since 1980. In 1989, Pathfinder incorporated the goal of providing integrated employment services to individuals with disabilities into its organizational mission. The premise was that integrated employment not only "opens" more employers' doors, but also provides a needed service to people with disabilities who otherwise might not use a traditional rehabilitation facility.

In 1989, John Niederman, Pathfinder's CEO, joined the Huntington County Chamber of Commerce Education Committee and the county Industry/Education Partnership to promote the employment of people with disabilities. These committees discussed the results of a recent assessment of the county, which indicated that most young county residents planned to work outside the county after graduation.

These committees, Mr. Niederman, and the Lime City Economic Development Corporation, identified the county's common employment needs. They discovered that very little had been documented about employment opportunities with, and skills needed by, local companies. Pathfinder Services had had difficulty retaining people with disabilities in jobs, and the business community was concerned about employing our youth and other job seekers within Huntington County. Pathfinder Services and these community organizations determined that a computerized Local Job Bank, listing the characteristics of all jobs in Huntington County, would benefit both employers and job seekers. Employers saw this project as an effective way to inform the public, especially young people, about jobs in the community and avoid a county brain drain.

Although employers and the community supported the Local Job Bank concept, the Huntington County Chamber Education Committee decided to run a pilot project with two high school vocational classes to determine if the concept truly benefitted job seekers. The pilot project results showed that most students were uninformed about career choices and local job opportunities; providing information about local jobs helped students make career choices and influenced some students, who might have sought jobs elsewhere, to remain in the community.

Pathfinder Services and the Huntington County Chamber of Commerce marketed the results of the pilot study to 20 key local employers, who pledged $11,000 to the Lime City Economic Development Corporation to match a state Office of Vocational Rehabilitation grant. These local employers also committed many hours to analyzing their jobs for a Local Job Bank. The Indiana Office of Vocational Rehabilitation grant became effective January 1, 1992. This agency saw the project as a way to increase job retention of people with disabilities.

This project will have multiple results. All job seekers, with and without disabilities, will receive a Local Job Bank Handbook, informing them about all available jobs. The handbook will have a detailed analysis of each local employer and provide information on: union/non-union affiliation, job knowledge and skills required, speed and accuracy requirements, physical and environmental demands, experience and educational requirements, wages, benefits, and the number of jobs available at each business. This information will help match job seekers and employers, and will help young job seekers successfully transition from school to work. The Local Job Bank information will also enhance Pathfinder Service's network with local high school guidance counselors, local college placement offices, local Vocational Rehabilitation counselors, and the state employment and JTPA local office. Networking ultimately will result in job placements for people with disabilities. Gathering the job analysis information from every employer will also be an opportunity for Pathfinder to market its various employment services.

Current status of the project is as follows: Software (Oasys from Vertek) was purchased, and job analysis has begun. The Workforce Services Director from Pathfinder Services met with each employer's Human Resource Director to explain the project and initiate a jobsite analysis. Job analysis is time-consuming for employers, so short-cuts were found making the job analysis very easy to read and complete. It is projected that 80 percent of all county employers, and 95 percent of employers with 100 or more employees, will participate. To date, there has been almost total employer involvement in designing and implementing the project and employers have been educated on their responsibilities under the Americans With Disabilities Act (ADA).

As project leader, Pathfinder Services realizes that the Local Job Bank will enhance employment opportunities for people with disabilities. The Local Job Bank will provide information leading to better job matches, especially given the employment impact of the ADA. Also, as Pathfinder analyzes every job in the community, the agency achieves expertise in manpower development, as well as the ADA. Many employers are consulting with Pathfinder in writing job descriptions that comply with the ADA.

The Local Job Bank Project will ultimately increase retention rates and social integration for workers with disabilities. It is an example of how local resources, such as the Lime City Economic Development Corporation matching funds, can combine with state funds to improve employment opportunities for people with disabilities.

For more information contact Pathfinder Services, Inc., P.O. Box 1001, Huntington, IN 46750; 219/356-0500.

LEADERSHIP DEVELOPMENT

John Halko, Acting Director

This is a description of a short-term project done in the most rural county of New Jersey, which happens to be part of our independent living center's catchment area. The initial purpose, as set by DIAL Northwest's director and advisory council, was to respond to the desperate requests from Warren County residents with disabilities who were extremely frustrated by the isolation and the lack of resources available to them.

Since Warren County represents one-third of our catchment area and since geography and lack of staff hindered our ability to reach and work with folks there, it was decided that DIAL Northwest's director would secure volunteer help from a college and work with them on a short-term basis. A very aggressive campaign to bring about quick changes in Warren county was initiated. Volunteer support was increased to run the Northwest (NW) office. Since the director is the only full-time professional staff person and could not be spared too long, an unconventional community organizing approach like that used in the Civil Rights Movement of the 1960s was adopted to expedite our plans.

The approach was to recruit people with disabilities and train them in leadership and advocacy skills to identify and resolve their most pressing issues. The hope was that their success would breed a competent community-based organization linked to DIAL and integrated into Warren County. In this way, they would have their own microcosm activist organization that could continue any momentum we got started. It worked!

We gathered a small group at first that was willing to work with us to make changes. The main obstacle to overcome immediately was getting the limited para-transit to work for us and bring people together to build camaraderie for action. Using the media through public service announcements, radio shows and coverage of our "actions," we quickly raised the profile of people with disabilities and the consciousness of the community at large. By pointing out the transportation crisis and special needs of people with disabilities and getting public support, we were able to get transportation for our meetings/trainings. DIAL leaders/members from our other two counties met with Warren folks for peer counselling and encouragement; social events were also used to bring folks together.

The primary issue identified by the Warren folks was to convince the County Freeholders to establish an Office on the Disabled for them there. Our experience in other counties demonstrated that this was the best way to ensure ongoing coordinated support services and a forum and vehicle for residents. The political powers had a long history of non-responsiveness to the disabled community. To encourage them to respond favorably, the group networked with all the other major human services in the county (through the Protective Services Task Force sub-committee of the Human Services Advisory Council) and formed a large coalition with the expressed purpose of lobbying for an Office on the Disabled, "our cause."

The climax occurred at a Freeholder's public meeting when our group monopolized the agenda by having 10 members group deliver prepared testimony about the needs of people with disabilities there and their determination to get an Office on the Disabled established to meet those needs. DIAL videotaped this event and uses it as an advocacy training tool. The public in attendance that night applauded and supported our efforts, forcing the Freeholders to adopt a resolution complying with our demands. Today, a year later, our group forms the core of a permanent Disabled Advisory Committee to the Freeholders and the Office on the Disabled is about to open!

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When outreach started into Warren County in Sept. 1990, only two residents were actual members of DIAL NW. At the end of our special project in May of 1991, 30 were active members and 74 people with cross-disabilities from Warren had met and were networked into a Coalition of 110 that included professionals from other county human services agencies. The latest demographic data from Bernard Berkowitz of Rutgers University, NJ, indicates that there are approximately 7,000 adults with disabilities in Warren County. Therefore, our short-term project reached 17 percent of this population. The Warren Department of Human Services estimates that 65 percent of the people with disabilities living there live at or below poverty level as defined by the Social Security Administration.

At the time this project was done, none of DIAL Northwest's total budget of $80,600 was allocated specifically. Since our funding is to provide services to three counties, it is reasonable to assume that approximately one-third of our budget could be available to each area.

It is important to note that two senior college interns provided free services over their six-month term with us, and eight volunteers helped man the NW office in Sussex County that provided all the in-kind support services such as telephone and secretarial assistance.

Estimated costs for the intense six-month project with three months of follow-up are $8,600, one-tenth of our operating budget. This includes 50 percent of the NW director's salary for six months, staff and client travel, telephone, postage and miscellaneous.

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The process we used to accomplish this project was a replication and microcosm of a project we did in Morris County from 1985-1988. The Warren project cost one-tenth of that project and accomplished relatively the same things in one-third the time.

People with disabilities are now a real presence in Warren County, NJ. Their success as a group and individually has enhanced self-esteem and earned them respect. They are now getting out into the community and participating and contributing on many levels. They play an active role in determining services through their advisory council and are in direct contact with the county policy makers (Freeholders). They are no longer invisible and powerless. More people are setting and achieving personal goals, changing lifestyles and displaying higher levels of independent living. Their families now complain that they are out too often and too busy!

Their advisory council is charged with the task of guiding the development of their office on the disabled, funded by the county. Through the council and other county committees, DIAL members/leaders serve with and are networked to the other human services providers. They now stand a much better chance of getting their fair share! Heretofore, the other service providers described the same frustration DIAL NW has in trying to reach disabled folks in Warren county. Based on what DIAL hears from consumers, providers seem to be much more responsive -- especial when their affiliation with DIAL is mentioned when attempting to access and/or secure services.

The most significant change occurred in the way that the county's para-transit system (the only source of adapted transportation available to the disabled public) interfaced with the disabled community. Before this project was done, they provided very limited and ineffective service to the disabled community at large. Instead, they catered to special interest groups like the Multiple Sclerosis and Muscular Dystrophy Societies that had the money to provide more services to their members through paid contracts with para-transit. Now, people with all types of disabilities comprise DIAL NW. This system seems to have cleansed itself of its reputation for lack of courtesy and unreliability.

In attempting to create services or improve existing ones in rural America, one is inevitably faced with issues of time, money, resources and practicality. This project was able to accomplish a maximum amount of positive change in the least amount of time (six months with three months follow-up) and with very little money (10 percent of the ILC's operating budget). By adapting the aggressive community organizing techniques used by the great leaders of the Civil Rights Movement, we minimized the negative effects of rural settings on our ability to expeditiously set goals with, by and for people with disabilities. The priority was to find people interested in making changes and bring them together. It was necessary to force the para-transit system to work with and for us. This project was expedient and effective.

Because it was created by and for people with disabilities to meet needs and goals set by democratic process, they "owned" it. It was purely a grass-roots effort proving, once again, that the power of the people is alive and well. It clearly demonstrated that an activist approach by those with a vested interest can succeed against all odds. Obstacles were overcome, people empowered, and permanent structures put in place to continue the momentum.

For more information contact DIAL Northwest, Inc., No. 7 Boardwalk, Sparta, NJ 07871; 201/729-7155 (Voice), 201/729-3396.

Cultivating Careers

THE COMMON THREADS

- **Rural young people need the option of choosing to leave their hometowns, getting a picture of their place in the world, and, if they want, returning to their rural hometowns on their own terms.** To untie the apron strings we must include all students in "Life Skills" training programs. We can no longer assume that students, with or without disabilities, will automatically make informed career decisions, based on their awareness of all available options and resources. The employment world is complicated and increasingly more-daunting to young people. Perhaps every prospective worker needs a "job coach" or "job developer" who can look at the big picture of the person's life and include employment in personal development and life choices. Person-specific, rather than disability-specific, futures planning is critical to career development and we need to get better at doing it for everyone. Perhaps disability services providers should think about marketing their expertise more broadly.

- **Work to change legislation regarding:** health insurance benefits; **disincentives to work (loss of benefits)**; and welfare reform. Vocational Rehabilitation agencies are no longer under the "20-hour" gun (a rule which tied eligibility for supported employment services to the individual's capacity to work at least a 20-hour week); a person can work as little as two hours a week, if that meets his needs. Regulations must accommodate flexible, client-designed work schedules. Avoid turf issues among employment-related agencies. **Service providers need to function as a "benefit protection service" which can use the system to help consumers get the career choices they want, while still protecting their benefits.** If a person gets Supplementary Security Income (SSI), the Plan to Achieve Self-Support (PASS) or Impairment-Related Work Expenses (IRWE) programs can offset income and protect SSI benefits. **Educate local Social Security office employees about these programs.** In each state, there is a key person familiar with PASS and IRWE programs; if local Social Security people don't know the regulations, contact the expert. Medicaid laws don't parallel Social Security laws, but should.

- **Listen to the consumer's career vision; don't impose your own.** For example, a young woman worked with several job coaches and job developers who urged her to take a job involving one of the "3-F's" (food, flowers, filth). She failed at all jobs in these fields. A friend helped her find the job she wanted and she's stayed with that job for four years. How does the person value work? Some people want a job, not a career -- allow consumers to draw their own conclusions. Conduct consumer satisfaction surveys to determine if your program is accountable and responsive to consumers. Our job is to "facilitate" employment, not "support" it. **Give a person as many options as possible: a person should be able to choose to stay in the home community, move to another community, or to leave now, with the option to return later.** We often create a closed job system in which we prepare people to do jobs for which there is little or no community demand (i.e. Sheltered workshops frequently train people to recycle aluminum, glass, etc. There is little community demand for these skills in rural areas). **Flexibility is a must**: a person may need more than one job to survive or several people may share one job. Develop new integrated ideas and strategies. Think beyond retraining a person to do something different after he or she acquires a disability; many people with disabilities prefer to continue in their chosen career. How can you help them do that? If the person doesn't have clear career aspirations, explore ways to discover what the person wants. Test results don't always translate to career or life choices. **It's critical to conduct job sampling and assessment of interests and**

abilities in actual job settings. Placement changes don't mean failure; they're part of the "industrial evaluation." We all change jobs occasionally; people with disabilities need this freedom too, without being labelled as failures. Be honest; job competition is intense and most people have to work their way up the ladder. **Separate career development from job development. First, assist people in getting jobs that provide their basic needs, then think about career choices.** Struggling to survive leaves no time or energy for career development.

- There are negative aspects to employment in rural areas. Many jobs are entry-level, with low wages. Parents want their young people to stay in the hometown. There are few jobs available and limited types of jobs. Transportation to jobs can be a problem. Educational and training opportunities are limited. Housing may be unavailable or inadequate. Opportunities to take risks are limited; and consumers may fear losing benefits if they work. Rural career development is linked to rural community economic development. Look at each community and ask, "Is this a good place to live? Are people happy living here? Is relocation a better option?" Work with rural economic development agencies to make rural communities a better place for everyone to live. Develop creative long and short-term goals for careers in poor rural economies. Now is the time for rural agencies to take the lead in career development for people with, and without, disabilities. Get the community involved; show role models with disabilities working in the community. **Network with business advisory councils**: What jobs are available? What skills are needed? Does a person need appropriate assistive technology or access modifications to pursue a specific career choice? ILCs can enhance career development.

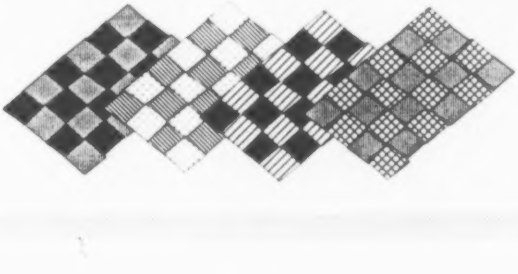
Rural Strategies

One rural program employs consumers to write PASS programs for other individuals.

Alaska has block grant development programs, including "Work is What You Make It." Individuals decide what their work will be, submit grant requests and earn stipends. The work might be cleaning up their own living quarters or subsistence hunting and fishing -- this is work and, as such, is worthy of support. Later, when the person is ready, he or she may move on to more conventional employment. (This is discussed more thoroughly in the Rural Supported Employment Forum Report.)

In **Alaska**, tribal chiefs or village councils are treated as the local employment agency. This empowers villages and educates them on how the system works. Local control coupled with outside funding works.

A **South Carolina** craft village employs people with disabilities to make Appalachian furniture, candles, pottery, etc. The village is a creative, self-sustaining solution to limited rural employment opportunities.



WEAVING NATURAL SUPPORTS

Rural specialized disability services are often few and far between. The greatest source of assistance is natural support systems. According to a 1981 definition, **"Natural structures of community support include the efforts of people with disabilities to help themselves, assistance provided by immediate and extended family members, and support offered by friends and neighbors. It also includes assistance provided by voluntary associations (e.g. churches) and generic services available in town (e.g. libraries)."** (From: Berger, P. & Neuhaus, R. (1981). To empower people: The role of mediating structures in public policy. Washington, D.C.: American Enterprise Institute.)

WEAVING NATURAL SUPPORTS means redefining existing rural entities as resources that can help people with disabilities to lead healthy and independent lives. In a really integrated community, there would be little need for "special services" for individuals with disabilities. Anyone in the community would have access to the same options to address a range of needs. Today when you go to the grocery store or discount store, there is frequently a powered mobility device, to help the shopper move more readily through the aisles. Use of these devices isn't limited to people labeled as having disabilities. Usually, if you think the cart would be helpful, you can get the key and use it. By the same token, use of a pay phone with volume adapters isn't limited to people diagnosed as having a hearing limitation. These are only two examples of how communities are providing regular services and access to a broader range of members. As ADA takes effect, expect to see more and more regular access built into the community.

While specialized service systems may be necessary for many people at different stages of their lives, specialized services should no longer dominate policy and planning discussions. We should challenge the basis for expanded funding of "separate but equal" services. It is time to explore how many services, currently viewed as "special," could be provided by natural community supports. Rural communities lack "special" services and may be able to provide leadership in developing integrated communities.

LISTENING AND CARING: EMPOWERING THROUGH SHARING GROUPS

Ray Risho (Presenter)
Susie Risho

A **relevant aspect** of church growth in the 1970s was the refinement of the previously inspired "growth by groups" or "home group" concept, which sought to provide personal nurturing and spiritual development for a church's members. The merits and success of this vital movement within a church were evidenced by personal maturity and a significant increase in membership. A dilemma these groups confronted, however, was that most (even the most dynamic) would eventually become static and, turning in upon themselves, they would decay, die and disappear forever. The sharing group I will describe began in 1979 as a typical home-group Bible study. Sponsored by the Covenant Church of Missoula, Mont., my wife, Susie, and I became pastoral directors of a group that comprised three families, four singles and one adult with a disability.

I first witnessed the effectiveness of the home group method of operation in 1968 and was impressed with the results achieved in developing personal relationships among its members. The Covenant Church was operating on the cutting edge of its pastoral care program when, in 1974, it attempted to incorporate people with developmental disabilities into the life of the church. Initially, church members were inclined to invite people with disabilities to attend only church services. Eventually, however, invitations were extended to include participation in the church's home-group program. The church's endeavor was to be all-inclusive, so each home group initially comprised approximately 12 people, including at least one adult with a disability.

Since several members of the church were professionally involved in the human services sector of Missoula as licensed social workers, group-home managers, etc., recruiting participants occurred rather naturally. Extensive teaching, using examples such as Mother Teresa of Calcutta and Jean Vanier, innovator and founder of L'Arche movement in France, was offered to church members who had never had an individual relationship with a disabled person. Boundaries were expanded remarkably and numerous obstacles overcome. Thus, opportunities to humanize a segment of the population that had for centuries been stripped of its humanity were amplified. The encouragement to model one's life according to the biblical, Deuteronomic principle of "loving your neighbor as yourself" was a beginning. Nurturing a personal desire to serve people with developmental disabilities was perceived not as a problem or a job, but as a privilege. Learning to listen was an important building block laid in the foundation of caring. We reasoned that a person cannot feel cared for if no one is listening.

I noticed that during portions of the home-group meeting, the participants with disabilities became practically invisible when they were no longer able to interact or keep up with the pace of the group. Essentially, they faithfully attended each weekly meeting but were not full participants. Usually they sat silently for two or more hours; often they would fall asleep. Further assimilation required more intentional focus on personal sharing. Close attention to and sincere concern for the participants with developmental disabilities ensued.

Often our sharing group needed replenishing as church members moved away from Missoula. We invited more individuals with disabilities who attended the church but who were not involved in a small sharing group. We had become personally acquainted with most of our church's visitors with disabilities, particularly through a monthly event we initiated and called "friends meeting." However, other pastoral directors, who at this time assumed that personal growth was achieved through the process of insulation, were not inviting the disabled into their groups. Responding to what we saw as a dire need, we gradually received more participants with disabilities into our sharing group. By the end of the 1980s, our group included about 18 participants with disabilities, one volunteer assistant and two group leaders.

What began in 1979 as a typical home-group Bible study with only one member with a developmental disability has blossomed by 1992 into an independent outreach, sharing and peer support group of approximately 25 adults with developmental disabilities. Members, who meet bimonthly, are drawn from numerous sources: state-run and private group homes, personal care facilities, assisted living programs, and referrals from Community Case Management Services. Participation is voluntary, with no imposed criteria for involvement. Leadership and direction of the sharing group emphasizes enrichment and personal well-being, enhancing a quality of life desired by all people. Although this model can be developed within a secular format, we incorporate the life and example of Jesus Christ, which enables group members to experience the biblical concept of basic community found in the "oikos" or "household of faith." New members are not recruited by the group leaders, but are assimilated into the sharing group by peer initiation and invitation.

Our defined purpose has been to respect each individual, caring deeply for their needs and well-being. During the week of the bimonthly meeting, participants are contacted through numerous service organizations, and transportation is arranged. The sharing group is divided into six specific segments: arrivals and socializing, personal sharing, corporate prayer, the lesson, refreshments and one-on-one intimate sharing. The gathering focuses not on progress or production but on the long-term process of developing positive self-awareness and esteem through the cultivation of personal spirituality. There seems to have been little investigation into spirituality and faith enrichment of people with developmental disabilities. Exploring personal insights and gifts allows each member the opportunity to develop relationships in the workplace, home and social settings.

Meetings begin at 7:30 p.m. Each participant is greeted personally and casual group sharing follows. At 7:50 the group is collected and arranged in a large circle, which enhances personal sharing. The importance of a leadership team, which includes a group leader and an overseer, is critical at this stage. The group leader addresses each individual in an intentional manner, inviting the participants to talk about themselves.

There is no criteria for what may or may not be shared. Someone may wish to describe a personal struggle or a special event in their life, while another may merely describe what they had for breakfast that morning. The overseer monitors the entire group, encouraging participants to focus on and be attentive to the sharing individual. The overseer ensures that no one fades into the background or is ignored and that all participants get to share. Numerous personal needs expressed in the sharing time are listed and included in the corporate prayer time, which lasts from five to 10 minutes. The group leader usually officiates, but encourages all members to take part.

The following half hour is devoted to the Bible lesson of the week. The lesson is developed in such a way as to add relevance to everyday living situations. Continuity within the sharing group is provided by the two co-directors, who assist participants in understanding and articulating how they feel. The goal is to process personal conflict and struggles, strengthening the learning process as it relates to an awareness of others' feelings, forgiveness of others and expressing care for others. Several members take special pride in their reading ability and bring their personal Bibles to the meeting. While the group leader conducts the lesson the overseer, attempting to diminish the "teacher-directed" format, draws members into group discussion of the lesson. For instance, the overseer may use a subtle humorous criticism of the group leader's topic. When he senses the group losing its focus, he will insert a ridiculous comment about the content, causing the participants to rise to the defense of their group leader. Unsuspecting, they reassure the overseer that they understand the lesson by vigorously challenging his comments.

Relying on our own creative resources, Susie and I had developed our own Bible lesson outlines for the past 12 years. However, in 1991 a more formal lesson plan was purchased. A course developed by Laurie Skow-Anderson entitled "I Live in God's Love" seemed to meet our needs for about nine months. Several important topics appear frequently within the group and are examined effectively by Skow-Anderson: transitions in living and the conclusion of intimate relationships as obstacles confronted when moving into a new living arrangement; developing friends of the opposite sex; family life; grief and the loss of an important person; getting along with friends; and caring for others.

Before the lesson ends, the overseer prepares refreshments and notes those members who have expressed a special need during the meeting. The lesson is closed and the group is dismissed for refreshments and casual conversation. During this time, while one team member monitors the refreshment table, the other meets privately with any group member who had expressed a desire to share a personal matter. Group members often are eager to participate in one-on-one conversation with a team leader, and numerous personal obstacles are dealt with and resolved at this time. Occasionally follow-up may be necessary, and an appropriate service provider will be asked to intervene. Although solving a personal dilemma in a few minutes is usually impossible, simply talking and praying with someone who will listen intently eases stress immensely. By 9:15 p.m. all members have departed.

The success and steady growth of the group may be attributed to the absence of the need for personal justification. Our contemporary society bases our dignity, worth and value on personal justification; thus the common question, "What do you do?" Society tends to see people with developmental disabilities as "unjustified" -- as "consumers" and the recipients of social services. Following a disabling accident, clinical psychologist Fredrick R. Linge poignantly described his struggle to regain his independence: "I was to some degree at least justifying my existence." An adult with a developmental disability may never achieve a personal justification based on a criteria of self-control or by making a normative contribution to society. The ideal the group leaders choose to exemplify is forbearance, refraining from enforced obligation.

Organization and operation of the sharing group is maintained entirely through volunteer participation. The scarcity of resource volunteers who are able to make the long-term commitment needed in this endeavor is a chronic problem that hinders potential maturity and growth. There is a definite need to restructure and expand, possibly by using the cell-group model described by Carl F. George in his book "Prepare Your Church for the Future." This model counsels that eight people is an appropriate number for one person to nurture. In the fall of 1992, the sharing group will be divided into thirds. All current members will participate one week per month within a smaller, nurturing group in order to promote more intimate sharing. The entire group will continue to come together monthly instead of bimonthly.

Recently a longstanding participant of the sharing group experienced a physical crisis that required assistance from a personal care-giver while he recovered. The care-giver, accompanying the participant to a meeting for the first time, was greatly impressed by the intensity and depth of caring in the gathering. The participants encounter love and marriage, death, hospitalizations, abusive parents and all sorts of other significant experiences. All people appreciate and want care, understanding and comfort. The sharing group has been a meeting place addressing human needs that are often not satisfied in the workplace or within the home setting. Our hope is that all individuals, whatever their circumstances, may have a safe setting to share their lives with others.

For more information contact Risho's Adult Day Service, 302 South 4th St. West, Missoula, MT 59801; 406/549-0752.

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USING COMMUNITY COLLABORATION TO INTEGRATE CHILDREN WITH DISABILITIES INTO EXISTING RECREATION PROGRAMS

Michelle S. Davis, Family Resource Specialist (Presenter)
Linda L. Wilson, Community Resources Coordinator

Recreation is a natural part of family life. Parents routinely enroll their children in swimming lessons, or have a child playing community team softball or participating in scouting. Yet for families of children with disabilities, such opportunities are infrequent or unavailable. Families of children with disabilities rarely participate in recreational programs; this "linkage breakdown" discourages development of natural family recreational activities. The breakdown is due, in part, to recreation programs' inability to meet the individual needs of children with disabilities.

This paper describes the activities and methods of Project REaCH, a special project of the Community Resources component of the Family, Infant and Preschool Program in Morganton, North Carolina. Project REaCH aimed to integrate children with disabilities into existing community recreation programs.

Method

The method was a simple but effective "social network-building" model linking recreation programs and children having disabilities. Members of a social support network helped children with disabilities (as needed) participate in existing recreation programs. These programs included, but were not limited to: gymnastics classes, art classes, swimming lessons, roller skating, toddler playschool program, summer day camp programs and girl scouts.

The project was both needs-based and consumer-driven. Family recreation needs (both of the parents and of the child with a disability) were identified using a needs assessment model described by Dunst, Trivette, and Deal (1988). The model enables the family to identify wishes and aspirations that will enhance its functioning. The model mobilizes supports and resources, and uses helping behaviors to enable and empower participants. Our target population included families of young (3-12 yrs) children with disabilities. The Family, Infant and Preschool Program, public schools, and other agencies and programs serving children with developmental disabilities recruited families who were interested in community recreation programs for their children. We contacted these families and assessed their recreation needs. The goal was to match available programs with desires, allow the children to meet other children and have fun.

Project REaCH provided both direct and support services. Project staff helped the recreation staff plan activities for their classes, including adaptations for those children with disabilities. During planning, staff shared general information about different disabilities. More specific information and help was based on the individual needs of each child, with input from each child's parents. Volunteers and project staff provided help during each class or activity, as needed.

Each child with a disability was assigned a recreation attendant -- an "activity buddy." The activity buddy helped the child, as necessary, participate in community recreation programs. For example, a child might require individual help in swimming class. Project REaCH would assign an activity buddy to help the child during the swimming classes. The activity buddy might be someone in the family's personal social network (for example, a neighbor) or someone with special skills (such as a high school swim team member) willing to help the child participate in a recreation activity.

We recruited a cadre of activity buddies for this project. They were "nominated" by families, friends, neighbors, relatives, the Community College, area high schools, churches, community organizations, and other sources.

Many volunteers and staff members were local community college and high school students who received academic credit for their participation in the project. Project REaCH established a link between a local high school Child Development Class and a public elementary school's Afterschool Care Program. Child Development Class required that students work directly with young children. Students were trained as activity buddies for the children with disabilities; the students fulfilled their class requirement and the Afterschool Care Program's children with disabilities were able to fully participate in its daily recreation activities.

During the summer months, many older children just "hang around" the local recreation centers. We're exploring a collaborative effort to recruit these young people as volunteers to help younger children and children with disabilities participate in the centers' programs. In return, volunteers would receive incentives such as free swimming, tennis lessons, certificates of appreciation, etc.

Evaluation

The project was evaluated according to three criteria:

1. Were the project's activities carried out as planned? (Were the desired number of

families served? Did it provide adequate hours of service, etc.?);

2. Was the project effective in terms of family usage, family and child satisfaction, helpfulness to families, etc.?; and

3. Did the recreation center and activities become more accessible to children with disabilities?

Recreation department staff, parents, and volunteers provided feedback. We tracked the number of families participating in the project, and documented their increased use of recreational opportunities. This project increased use of existing recreational opportunities by children with disabilities and their families, and increased feelings of family and individual well-being and self-sufficiency. Recreation personnel also became more accommodating of the individual needs of children with disabilities. We expect the social network-building model to be replicable and to increase recreation opportunities for all people with developmental disabilities.

Conclusion

The collaboration of Project REaCH, the high school and community college teachers and students, community recreation providers, and families enhanced our community's ability to provide recreation for children with disabilities. REaCH and its cadre of 30 volunteers have been a resource to 50 children and their families, and to 12 community recreation providers.

Although this project was funded by a special grant, we hope to continue building linkages between families and recreation programs. The Community Resources Component of the Family, Infant and Preschool Program is responsible for continuing the Project's activities after the grant period ends. Using recreation facilities will become an ongoing, natural part of each family's support system and this project will serve as a liaison between the families and recreation programs.

For more information contact the Family, Infant and Preschool Program, 300 Enola Road, Morganton, NC 28655; 704/433-2826.

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WEAVING NATURAL SUPPORTS

Keri Helms, Independent Living Specialist

ALPHA ONE is a community-based nonprofit independent living center that was created in 1979 by myself and a few other people (consumers at that time) who were interested in trying to develop independent living services in the state of Maine. As you know, in 1979 the first formal funding from Congress was made available to 10 states to develop Part B independent living centers, and Maine, fortunately, was one of those 10 states.

So that first Title 7, Part B money served as the original funding stream in supporting the development of the organization. At first we were pretty much focused on providing information to people: peer support services, working with people to develop their independent living skills, doing a lot of community advocacy around the issue of architectural accessibility and also working with the Legislature to establish personal assistance services in Maine. Although we had only a small budget at the time and a small staff consisting of only two and a half people, we were providing the core services that ultimately served as our foundation and our base of support for expanding the organization over the past 10 years.

It was evident to me in 1980 that a new nonprofit such as ALPHA ONE had to take a different focus from the traditional nonprofit that would ultimately come to rely on federal funding for not only its maintenance but its growth. Ronald Reagan was coming into office; it was clear that he had decided that the federal trough was going to be tightened. So very, very early on in the history of this organization we worked with the state vocational rehabilitation agency to establish a fee for service.

I felt all the time that the services that we had developed and were offering had value to them, and what was necessary was to market the services and the products in such a way that other people would have that same perception and have that perception to a point where they would be willing to pay you an hourly rate if you went out and gave them a consulting or information on accessibility. So that whole philosophy and mentality was woven into the organization very, very early on in its roots, and it served to help the organization grow in a number of capacities.

At the same time, around 1982 or '83, the state of Maine, like the rest of the country, was beginning to surface from its recession and state resources were beginning to flourish. With the de-emphasis on federal funding at the time, it became obvious that state government was a source of funding that needed to be tapped and used to create new programs, particularly in the independent living field.

So ALPHA ONE struck out in that mode and we approached the legislature in a number of the areas. We were successful in getting them to fund personal assistance service, we were successful in starting a driver education program here, and we got some state help to purchase a vehicle and equip it. We began to diversify and branch out a little and get some new programs going.

We also began to recognize the need to have some satellite offices, which we now call affiliates. Over the course of the next five or six years we developed three new offices -- one in Augusta, the state capital, one in the bay area and one way up north. With the development of these three affiliate offices and our home base in South Portland, we're pretty much secure in having a physical plan to service consumers in a decentralized manner across the state of Maine. From the beginning we had intended to establish a strong statewide network of offices and consumers.

In 1985, keeping in step with our original thinking of diversifying revenues, we did a statewide consumer survey of all the people we had assisted up to that point. We asked them a lot of questions, but specifically we asked them to identify for us some of the challenges and obstacles that they still faced in their lives. One of the resounding responses that we received was that many of them said they did not have a medical equipment or rehabilitation equipment dealer that treated them first as people, that understood that they were consumers who were interested in purchasing good state-of-the-art equipment as well as getting that equipment serviced and having service available on an around-the-clock basis.

Our consumers recommended that we do something about this, so I brought the results to the board of directors and strongly encouraged the board to endorse me to explore the pluses and minuses of creating our own for-profit subsidiary. Questions to look into included: Would there be an ethical conflict if ALPHA ONE, a non-profit independent living center, were to establish a for-profit subsidiary that sold equipment and provided services as well. Where would the capital come from? Given that we were running on fee-for-services and some contracts and grants, we could not use really any government money for the start-up of this company. And, if we created the company, what would be the relationship between the two: Would they be physically separated or under the same roof?

To be honest with you, when I first came back to the board with my recommendation, there was real debate as to whether or not we should get into the business of setting up a new corporation and selling durable medical equipment. Ultimately, we got the green light. Research uncovered a local oil company that had an entire health care division that owned durable medical equipment and supply houses throughout New England. So it was obvious that they may be a source of capital provided I had the opportunity to present to them what our intention was and try to trade capital for the fact that we probably had a somewhat captive audience -- people who had done business with ALPHA ONE would be likely to buy their equipment from its for-profit subsidiary, if we could establish one.

So, in 1986 we signed papers with Dead River Oil Company and formed a company called Rolling Edge, which we thought was a pretty clever name. As it turned out, no one knew what Rolling Edge did. We got a lot inquiries from people wanting to buy skate boards and bicycles; we soon learned it wasn't such a clever name. Later, we changed the name to Wheelchairs Unlimited and our non-profit organization became the sole owner of the company. We were able to get a small credit line at the bank in 1987, and the company has grown rapidly since then. We experienced a couple of profitable years. In 1990 we experienced pretty rapid growth and probably bit off a little bit more than we could chew and lost some money. But the loss wasn't significant enough to put the company out of business. The following year we made a little money again. I should say is that in terms of this company being a revenue generator to any significant extent for and supporting the independent living center in any significant way, that is still questionable at this point. If anything, the benefits of Wheelchairs Unlimited to ALPHA ONE have been mostly in the areas of referring people for services at ALPHA ONE who come in for equipment or supplies but don't know about independent living -- particularly elderly people and parents with children. ALPHA ONE has been more of beneficiary in that manner than it has for many windfall contributions.

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We didn't really know what the recipe for success was to start with, and I can tell you that six years later we are still searching for that recipe. But I think we have gotten a little closer. I want to emphasize that this is a tough business to be in and requires hard, clever, smart people. Originally, when we started we were giving away freebies and a lot of service and a lot of products. That was a nice to do. But what we learned over the course of time was that if you want to be profitable (and if you are going to be in business and you don't want to be profitable, you shouldn't be in business), you cannot give away products that have value. It is as simple as that.

If you really want to ultimately benefit your customers or your potential customers, you'll do your best to be profitable in an ethical way so that you can provide the kinds of things that they want: service, appropriate evaluations, appropriate products that are measured correctly.

So that nobody should take this the wrong way, I'm still as excited as I was in 1985 when I recommended us getting into this business to the board of directors. I'm very excited because of a number of things. Although we haven't made a lot of money, we have gotten involved in an arena that traditionally independent living centers have avoided for one reason or another -- financing mechanisms for a wide range of equipment and supplies that people need for independent living.

Weaving Natural Supports

THE COMMON THREADS

- There is much give and take in support systems between: professionals and families of people with disabilities; philosophies of paternalism and independence; disability services agencies (confrontational or educational?) and consumers. Citizens' advocacy groups can mediate conflicts, develop compromises, suggest alternatives. A problem-solving strategy is needed to develop formal and informal support systems. Look first at the individual's existing needs. What are desirable outcomes? What are the needs of the culture and the community? Do they supersede the individual's needs? As caregivers age, support needs change. Examine the caregiver's values and develop a support strategy that: coaches consumers on self-advocacy and independence; provides peer counseling; provides age-cohort advocacy; shares resources across agencies (aging and disability); and helps the consumer access any assistive technology that may enhance his or her functioning.

Rules for Natural Supports (not in order of importance):

1. Strive for interdependence, as well as independence.
2. Divest yourself of "professional" attitudes; be humble; talk and listen to people. Keep language simple and eliminate professional jargon.
3. Use common sense.
4. Don't assume a "professional distance" -- you're going to like some people with disabilities and dislike others. Everyone (including the person with a disability) has the right to be a jerk.
5. The person with a disability has a responsibility to help others.
6. Break or create rules whenever necessary.
7. Use common courtesy, but don't be unnaturally "nice" to people with disabilities or their families.
8. Providing natural supports may be uncomfortable at times (ex. when sharing grief or anger). **There is risk to being a natural support; you have to be prepared to share yourself, your time and your resources.**
9. **A disability is a very limited descriptor of an entire person.**

- Natural supports start with the family or extended family. In Indian cultures, the definition of family is broader. Respect the family; they can say "no" to your offerings. Families can include friends. Peer groups can develop into natural supports. Link people with others who have the same disability and deal with the same issues. Support groups need not be disability-specific, if the goal is to help the person deal with total life issues. Redefine services, agencies and professional roles. People deal with their disabilities in different ways; respect their individual styles. For a traditionally-raised man, modern one-to-one support systems may be too "touchy-feely." A better natural support for this person might be someone with whom to watch sporting events or play cards.

- Our society has a tradition of providing professional services (such as respite care) to people, which makes it difficult for them to approach friends and family for help. However, although natural supports are necessary to enrich the person's or family's existence and ease community integration, society continues to have an obligation to provide services. Don't allow natural supports to displace obligatory services. Be very careful in determining which natural supports legitimately supplement, rather than supplant, the services already received.

Rural Strategies

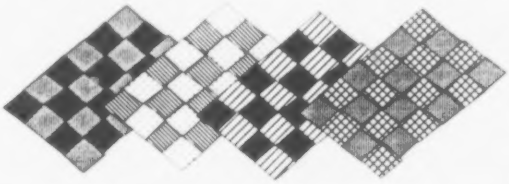
A **Wisconsin** support group for elderly people requires that each member draw another member's name out of a hat and call that person in the next week. The sponsoring program also matches elderly people with similar craft interests (knitting, quilting, woodworking, etc.) and acquired vision impairments. The newcomer quickly learns from the "old hand" that impaired vision doesn't mean sacrificing pleasurable activities.

Visitors to nursing homes are frequently not notified when residents die; there are no memorial services to allow visitors and other residents an opportunity to grieve. A **Montana** lay pastor instituted nursing home memorial services. He also held services for a member of his church's sharing group for people with developmental disabilities, which allowed the member's friends and co-workers to publicly share their memories of their friend. People with developmental disabilities need to share in life's passages just as anyone else does.

A support group didn't evolve into an actual natural support until its leader realized that the group's activities couldn't be bounded by time constraints. Some members weren't content to adjourn at 8:30 and dismiss the group until the next meeting. When the leader offered to provide members' home phone numbers to those interested, several people took the initiative to see each other outside of the meeting and formed friendships.

Acknowledging that recreation is a lifelong activity that builds self-esteem and feelings of success that carry over into other areas of life, a **Montana** program sponsors wheelchair basketball games. These games include community members without disabilities and family members of people with disabilities. The social interaction is a natural support. Recreation brings laughter and laughter is healing.

In rural **Maine**, mail carriers are trained to make eye contact and wave to ill, isolated elderly people. This reassures the people that someone is aware of their well-being.



CONCLUSION

Conclusion

TYING UP THE COMMON THREADS

The National Perspective

Mike Mayer

- **Empowerment means consumer control and choice; this is most important and reflects a fundamental change in our society.** The implementation of the Americans with Disabilities Act raises so many possibilities, but requires individual consumer support and self-advocacy.

- **Broaden disability networks to include nontraditional allies: business, local government and others.** The Association of Programs for Rural Independent Living (APRIL) will seek funding to do national leadership development in rural areas.

The State and Local Perspective

Linda Tonsing-Gonzales

- Consumer involvement in the political process is important. Organize rallies and mail-in campaigns, attend state legislature and city council meetings, and use the media to cover street theater events. Develop leaders who can become part of the disability network, coalition or advisory group and who can speak effectively to community organizations.

- The ADA is a vehicle for sharing with the nondisabled community; people with disabilities can provide guidance for compliance with ADA requirements. Participate in activities that ensure implementation of accessibility and systems change requirements. If you can't be actively involved, make referrals to those who are actively involved.

- Federal funding can be accessed creatively, even if the state can't match it.

The Education and Training Perspective

Doug Dunlap

New competencies must be taught in higher education and in all service agencies:

- Networking: Build coalitions, build relationships and share with those both inside and outside traditional service agencies. Consumers must be at the center of networks. Learn how to train employees, consumers and others to build these networks.

- Recognition of the individual's innate power. Offer your services, then get out of the way.

- Respect for natural supports, without romanticism. Society has the responsibility to provide some basic supports.

- Training as an intervention, involving equal partners sharing skills, whether in staff development or community disability awareness training.

- Development of community resources. The community is often a barrier, a "white space" in which nothing is available to people with disabilities.

- Empowerment of all groups encountering discrimination or stigma: people with disabilities, children, women, minorities, the poor, and homosexuals.

We are experiencing a paradigm shift:

From	Through	To
Therapy	Advocacy	Community

- Disability causes a loss of power. The first priority is to empower the person. Independent living philosophy applies to many other groups: people who have been physically, psychologically and/or sexually abused; immigrants; prisoners; people in substance abuse and mental health programs. Mental health professionals now acknowledge that traditional treatments are often insufficient. Traditional treatment locations (mental health centers and hospitals) are being challenged. The reality is that most people with mental illness will get better and can go on with their lives before being adjudged "cured." The independent living paradigm doesn't advise the person with a physical disability to wait until he or she is cured before proceeding with life. Living is a cure. The person with mental illness can also move on with life.

THE COMMON THREADS

Rick Offner

WE ALL WANT THE GOOD LIFE IN RURAL AMERICA.

- Negotiating Access: Access is a universal need; consumers must be empowered to negotiate for it through active involvement in the political process. Implementation of ADA requirements is an opportunity for consumers, their families and friends to advocate for change and educate the community. Transportation was, is, and will continue to be, the most challenging access problem for rural Americans with disabilities -- this is where the greatest creativity and the most rigorous cooperation are required. New-construction accessible housing can be financed creatively, as can modifications on existing homes.

- Networking Partnerships: Know your partners, their needs and those of your community. Forge linkages outside the traditional disability network. Don't hide behind professional jargon and rigidly-guarded professional and agency identities. The best formal partnerships frequently bloom from the warmth of informal relationships. Reciprocity is the key to equality between networking partners; each consumer, public or private agency, each community resource must be prepared to offer something of value for the gift received. Community integration is a two-way street; as people with disabilities seek to use community resources, people without disabilities can be encouraged to use the expertise of disability service providers.

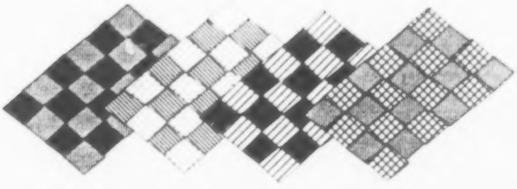
- Training Resourcefully: We are all trainers in some way and in many places. We inform, educate and reinforce the paradigm shift. Trainees will learn best if they're actively involved, if ongoing follow-up and support are provided, and if objectives, formats and content are customized.

- Cultivating Careers: Jobs are survival; careers are part of life. Rural economic development is tied inextricably to rural employment. Employment options are limited for everyone in rural areas, but more options increase the likelihood of a person's achieving a good career fit. Every person needs opportunities to try out jobs and careers, to move away or stay, to change direction occasionally. If we can develop rural economies, the increased number of options will benefit every worker.

- Weaving Natural Supports: Being rural requires participation in the community. As with networking, using natural supports requires reciprocity and looking beyond traditional disability resources. Be vigilant, however, that natural supports don't become an excuse for society to shirk its rightful obligations to its citizens. Natural supports should enhance, not supplant, other services.

The most important statement we've heard is, "I DIDN'T KNOW I COULDN'T DO IT."

Concerning language: We all have different backgrounds, histories, experiences. A cohesive language on disability is emerging, but in the meantime, look for the meaning behind the language. Don't turn off the speaker if his or her language offends; look for the intent behind the words. Listen carefully to a person's message, then begin to educate him or her.



FORUMS

NATIVE AMERICANS AND DISABILITY ISSUES FORUM

August 21, 1992

This informal discussion, hosted by **Julie Anna Clay** of the Rural Institute, focused on ways to improve service delivery for people with disabilities who live on reservations. Policy-makers, service providers, people with disabilities and family members shared their ideas and resources in a day-long examination of ways to overcome the obstacles to effective service delivery on reservations. The forum attracted 23 participants, including six tribal members, and Clay encouraged each to hold similar forums in their communities.

Borrowing from Native American tradition, the group broke into four "talking circles" for the morning session. To encourage participation by all members, each circle passed a "talking stick" (ranging from a willow branch to a rock), granting the floor to whoever held the object. In the afternoon, the four groups united in one large circle, and representatives of each group presented the problems and solutions their group had discussed.

Common threads that emerged from the discussion included: the importance of cultural sensitivity and awareness of the diversity of Native American populations; the need to establish service networks; and the essential role of tribal involvement in effective service delivery, access and other disability issues.

The following is a summary of the observations and suggestions that arose from the forum.

Cultural Sensitivity

Cultural awareness is an essential part of providing effective services to reservation residents, but it can be tricky since the culture varies from tribe to tribe. Service providers should learn the traditions, values and norms of the tribe and community they serve, but they must also recognize the individuality of the people within that community.

Efforts to understand the individual and the culture will help bridge the "trust gap" that can separate service providers from reservation residents, who are often suspicious of agencies and of outsiders in general. Specific suggestions raised at the forum include:

- Study the local way of life. Get to know tribal elders; learn the traditions of the tribal community. Learning the proper etiquette or ceremonies can help you gain credibility in the community.
- Don't make assumptions. Recognize the great diversity of individuals on the reservation, and find out about the person you plan to contact. Although it's important to learn about traditions, don't assume those traditions are followed by everyone on the reservation. For example, don't assume that an individual practices traditional religion just because he or she lives on the reservation.
- Do your homework. Before you contact prospective clients, know their religious background, family situation and special circumstances. Talk with family members or people in the community who know them.
- Get to know the people who know. Each community has at least one gathering place -- cafe, grocery store, post office, bar -- that everyone passes through, and at least one person in that gathering place who knows virtually everything about everyone. Getting to know that person will help you identify people who need services and find out about them as individuals.

- Be flexible and patient. Don't just show up, pass out brochures and expect the people who need your services to call you. People must trust you before they rely on you, and developing trust takes time and responsiveness to individual needs.

- Follow through. If you say you'll do something, make sure you do it. News of unreliability or broken promises will spread throughout the community, making it virtually impossible to gain any community member's trust.

Service Networks

The isolation and rural character of reservations make service delivery difficult, with great distances and scarce resources. Medical professionals, therapists, assistive technology and access modifications are all in short supply. Those services that are available come from varied agencies that generally do not coordinate their services or keep track of what other agencies are providing. As a result of that fragmentation of services, many people with disabilities fall through the cracks. Forum suggestions for improving service delivery on reservations included:

- Form service networks between the varied agencies that serve an area. Coordinated services will minimize service gaps and help each agency better serve their clients.

- Expand the definition of agency. Networks should include the community's natural supports. Identify the places where people gather and share information -- restaurants, grocery stores, post offices -- and make service information available at those sites. If you let the key people in those places know about available services, they will pass that information on to people who need those services.

- Identify needs. Work with the tribal government and community members to determine who needs what, and how those services could be made convenient.

- Make it easier for reservation residents to learn about available services. Find out about potential sources for technology and spread the word.

- Be persistent in dealing with agencies. The odds of getting the desired response will increase considerably if you make yourself and your concerns impossible to ignore.

- Centralize services in a tribal complex, library or some other place that people visit as a matter of course.

Tribal Involvement

Effective service delivery on a reservation depends on participation by the people of that reservation. Forum participants stressed the need to involve tribal individuals, government and organizations in varied ways, including:

- Recruit tribal members as service providers. Individuals who need services may be distrustful of agencies or outsiders, but they will listen to a peer.

- Provide detailed information about the Americans With Disabilities Act, and encourage tribes to adopt the act as a means of ensuring fair access for members with disabilities.

- Work with tribal governments to share resources and information. Inform tribal leaders of available programs and services, and involve them in strategies to provide those services to tribal members with disabilities.

- Encourage tribal college and high school shop programs to help provide needed access modifications and assistive technology devices.

- Enlist tribal members as speakers in education programs for agencies' service providers.
- Include tribal members on agencies' advisory committees.
- Hold public forums, similar to the Common Threads forum, on reservations to discuss needs and brainstorm ways to meet those needs.

Resources

For more information about Native Americans and disabilities contact the Rural Institute on Disabilities, 52 Corbin, The University of Montana, Missoula, MT 59812; 406/243-5467 (Voice/TT), 406/243-2349 (FAX).

RURAL SUPPORTED EMPLOYMENT FORUM

August 21, 1992

Andrea Cioffi and Roz Slovic of the University of Oregon, **Gwen Jensen** of New Horizons North of Ashland, Wisconsin, **Derrill Johnson** of the Alaska Division of Mental Health and Developmental Disabilities and **Millie Ryan** of the Alaska Division of Vocational Rehabilitation hosted this forum which focused on rural supported employment issues.

The keys to successful rural supported employment are persistence, flexibility and the creativity to experiment with sometimes unorthodox solutions. The successful rural supported employment program analyzes the local community and the local culture. What job opportunities obviously exist? What job opportunities lie beneath the surface, waiting to be discovered? How many jobs can one person do? How many people can share one job? How many ways are there to define "job," "work" and "career" -- and who makes up the definitions? If an employer isn't responsive on the first try, what about the second try -- or the fifth or the twelfth?

There are several resources that can help rural projects answer these questions:

The Employment Network at the University of Oregon is a national supported employment technical assistance project, funded by the of the Office of Special Education and Rehabilitative Services. It is one of two national projects; Virginia Commonwealth University in Richmond, Virginia, also provides technical assistance.

The goal of both projects is to increase the capacity and ability of communities and states to provide employment opportunities for people with severe mental and/or physical disabilities, including traumatic brain injury, developmental disabilities, mental illness, sensory impairments and others.

The Employment Network offers its support to state Vocational Rehabilitation agencies and other state agencies, self-advocacy and advocacy organizations, Rehabilitation Services Administration regional offices, and various regional and national organizations. Assistance is user-driven and individualized to state needs. The staff offer diverse, flexible methods that adapt to both local community and state economic development plans. There is an emphasis on mutual accountability of agency, service provider, employee and employer. Networking within and across roles is important; staff provide suggestions on enhancing networking.

Employment Network technical assistance includes:

- ongoing telephone support
- on-site technical assistance
- referral to other resources
- consultation
- seminars and forums

All information is the most current available. (Note: These technical assistance projects are funded through October 1993.)

New Horizons North, of Ashland, Wisconsin, helps people with disabilities get and keep community jobs working side-by-side with typical employees. The program is located in northern Wisconsin on the south shore of Lake Superior and serves two counties with a total population of 30,000. Five communities, ranging in population from 300 to 9,000, have supported employment sites. Although local unemployment rates are high, the project has placed 60 individuals with disabilities in 28 businesses at competitive wages.

New Horizons was originally a sheltered workshop, but its mission now is to assess, integrate and support adults with disabilities as they perform meaningful paid work in the community. The process is not without obstacles (New Horizon staff prefer to think of them as "challenges to creativity"). Transportation, as in most rural areas, is definitely a challenge. Families need encouragement to allow their members with disabilities to grow and take risks. Employers need to be educated on restructuring existing jobs to accommodate more workers and to allow existing employees to use their time more productively and efficiently. For example, the New Horizons staff had noticed that overworked local nursing home staff did not have time to both bathe patients and supply fresh bedding. Now supported employment workers in the nursing home make up beds while patients are being bathed. This creative supported employment arrangement works to the benefit of patients, nursing staff and supported employees.

Arranging good job matches is essential. For example, a gregarious, energetic person works at the local grocery where she has lots of personal contact with employees and customers. Several individuals working in relatively close proximity can share a job coach. More than one person can share a job, such as the pair who cooperatively feed a bank's paper shredding machine or the individuals who share a job at a 24-hour, seven-day-per-week business. New Horizons staff is encouraged in its creativity and persistence by the increasing community acceptance of workers with disabilities and by the increasing independence and personal growth of those workers.

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The Alaska Division of Mental Health and Developmental Disabilities is adapting its supported employment model to fit local cultures and conditions. Take, for example, the story of "Shaun":

Shaun is a 20-year-old man from a remote Athabascan village. He has a controlled seizure disorder (which requires that some activities be supervised) and developmental delays. When Shaun finished school, he and his family agreed that Shaun should stay on in the village. Shaun took a temporary fire crew job, but was left unable to support himself at summer's end.

State of Alaska agencies worked with the Tanana Chiefs Conference Developmental Disabilities Program and the local Village Council to develop an array of activities that would allow Shaun to support himself in the village. He works part-time in the village store stocking shelves, unloading freight and doing janitorial duties. Shaun supplements this income with wood cutting and hauling, fishing, trapping and hunting. Instead of a job coach, Shaun learns his job and subsistence skills from a local "Mentor of Subsistence Activities," who is compensated by the Division of Vocational Rehabilitation (initial phase) and the Division of Mental Health and Developmental Disabilities (long-term follow-up). The compensation is locally administered by the Tanana Chiefs Council and the Village Council.

The Division of Mental Health and Developmental Disabilities helped Shaun get the snowmobile, chain saw, fishing nets and other equipment he needs for his subsistence activities. Some of the equipment is purchased from local crafts workers.

Shaun's supported subsistence program exemplifies the best of rural supported employment strategies. It is creative; it is adapted to local conditions and culture; it provides local control and uses local resources; it adheres to the wishes of Shaun and his family; and it allows state agencies to interact with local organizations and individuals without unnecessary bureaucratic impediments.

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The Rural Institute on Disabilities sponsors a number of supported employment activities and projects.

The Rural Institute's Research and Training Center on Rural Rehabilitation (RTC:Rural) is developing a project to evaluate the use of natural supports for supported employment in rural communities. The project will compare rural and urban areas focusing on questions that include: what kinds, types and amounts of natural supports are needed to integrate a person fully into the rural workplace; who in the natural support system do job trainers provide support to; what kind of and how much natural support is needed to support a person in the workplace; and are natural support systems formed more quickly in rural areas than urban areas?

A second project of RTC:Rural profiles the implementation of supported employment in rural america. Although supported employment has been implemented in urban areas, a growing number of indications suggest the need for strategies to implement it in rural and remote areas of the country. This project will evaluate the extent of supported employment along a rural/urban continuum to better delineate the cost-benefit aspects of rural supported employment. The project will also profile successful rural supported employment models from various states.

The Montana Supported Employment Development Project (MSED) is another project funded to expand supported employment services for people with disabilities in Montana. Project staff offer technical assistance, training and support to service providers and assist legislators and consumers with long-term funding strategy development. The project involves consumers in all levels of service expansion, including policy development, project evaluation and needs assessment.

The Rural Supported Employment Coalition is an informal national group of rural service providers who share supported employment resources. The group is coordinated by MSED at the Rural Institute.

Resources

For more information on supported employment technical assistance contact The Employment Network Specialized Training Program, University of Oregon, Eugene, OR 97403-1235; 503/346-2487 or 503/346-2473.

For more information on employing people with disabilities in community jobs contact New Horizons North, 811 W. 3rd St., Ashland, WI 54806; 715/682-7171.

For more information on adapting your approach to supported employment to fit local conditions or a resource list available of training materials developed by the Alaska Supported Employment Demonstration Grant contact the Division of Mental Health & Developmental Disabilities, 1001 Noble St., Suite 450, Fairbanks, AK 99701; 907/451-6884 or the Division of Vocational Rehabilitation, 801 W. 10th St., Suite 200, Juneau, AK 99801-1894; 907/465-2814.

For more information on the supported employment efforts of the RTC:Rural or the MSED Project contact the Rural Institute on Disabilities, 52 Corbin, The University of Montana, Missoula, MT 59812; 406/243-5467 (voice/TT), 406/243-2349 (FAX), 800/732-0323 (Toll-free).

RURAL MENTAL HEALTH FORUM

August 22, 1992

Rob Hess and Richard Schmidt of Idaho's Bureau of Mental Health and **Tom Seekins** of the Rural Institute hosted this discussion, which focused on issues of mental health services in rural communities.

Schmidt described a process of small grant awards used to develop local and regional consumer organizations in Idaho. Groups were encouraged to apply for grants ranging from $2,500 to $15,000 to address local organizational needs and community issues. A tremendous amount of work was accomplished. Perhaps more important, however, was the empowering process of project planning. This work has contributed to the emergence of a strong, statewide consumer-based organization addressing the needs of people with mental illnesses.

Some forum participants raised concerns that some rural communities may be reaching "saturation" points. This was particularly seen in relationship to the traditional location of institutions in rural areas -- out of sight and out of mind. Specifically, participants worried that if a disproportionate number of individuals with severe and persistent mental illness settled in a small community, community services might be stretched and a sense of intolerance might emerge. Clearly, participants were concerned that, apparently, little is done to prepare communities for addressing the needs of these individuals.

Much of the discussion focused on possible linkages between independent living centers and services to individuals who experience mental health problems. While several participants reported successful cases, some concerns were raised, including:

- Independent living centers (ILCs) in rural areas may be a very good source of service and support for individuals with severe mental health problems. Generally, relatively few service providers in rural areas address the needs of people with a variety of disabilities. In areas served by an ILC, the center could provide an option for individuals with mental health problems.

- The disability movement has a lot to offer those in the mental health field. In particular, mental health services were described as focusing on helping individuals come to an understanding of their emotional and psychological issues -- the classic psycho-dynamic treatment approach. While this may be an important part of therapy, it is often dwelt on to the exclusion of functional issues in life. ILC philosophy accepts the fact of disability and addresses those functional life issues -- getting on with the tasks of living rather than dwelling on problems.

- While this functional approach may be a lesson ILCs could help teach, forum participants generally acknowledged that community health services could be called on for much more help in supporting the efforts of individuals with physical disabilities to live independently in rural areas. Such a connection was seen as offering benefits to the IL movement. This point was underscored by discussion of the underlying role of psychosocial issues in secondary disabilities.

- In any consideration of encouraging ILCs to extend more of their services to people with chronic mental illness, it is important to recognize that ILC staff may not have training or expertise in dealing with some issues. This is particularly true of the cyclical nature of some mental health problems. The concept of case closure, used by some ILCs, is not compatible with support of individuals experiencing long-term mental illness. Interestingly, several representatives from different ILCs were surprised to learn that others use the idea of case closure and felt it is not consistent with IL philosophy.

In either case, ILCs would have to re-orient toward longer-term support and be prepared for the cyclical nature of the disease.

◆ One major issue discussed at the forum involved discrimination between various disability groups and their service providers. The question is whether consumers of one service system, such as ILCs, would accept involvement and support from a system designed primarily for another group. This issue prompted a surprisingly heated discussion and suggested that intolerance exists in groups that have borne the brunt of discrimination. The consensus was that this issue needs to be addressed more openly.

In discussing secondary conditions of physical disabilities, Doug Dunlap raised the problem of the health status of people experiencing mental illness. Data suggest that mental illness can set the stage for significant health problems. Dunlap pointed out, however, that these problems are not necessarily related directly to mental illness but may be the result of disrupted socioeconomic status that may accompany severe mental illness.

In response, Hess asked the question, "What would the experience of mental illness be like, if the playing field were level?" Indeed, what would any disability be like?

Resources

For more information contact the Rural Institute on Disabilities, 52 Corbin Hall, The University of Montana, Missoula, MT 59812; 406/243-5467 (Voice/TT), 406/243-2349 (FAX). Or contact the Idaho Bureau of Mental Health, 450 West State St., Boise, ID 83720; 208/334-5528.

THE IDAHO MENTAL HEALTH SYSTEM: ITS SPIRIT AND ACCOMPLISHMENTS

Robert E. Hess, Chief Idaho Bureau of Mental Health

In **1990**, the Public Citizen Research Group and the National Alliance for the Mentally Ill released a national report rating state mental health systems. Idaho, which was ranked 46th in a report two years earlier, was ranked 49th in the nation. The report noted that the state routinely jailed individuals with a mental illness as part of the commitment process, was lacking in vocational opportunities, had no crisis beds, had only minimal case management and lacked many other basic services.

The report noted that the system was the lowest-funded system in the country but neglected to note that the two state hospitals had waiting lists. The report noted many weaknesses in the system and few strengths. This was unfortunate, as the strengths in the system have enabled it to make substantial progress in the past two years. Richard has noted one of those strengths, a growing consumer movement that has acted in partnership with the rest of the system to bring about change. Other elements that have played a significant role are the exceptional staff in the system, the vision of hope for an improved system and the fact that the system was in a state of crisis.

To bring about change, the system started to make its vision explicit in 1990 and 1991. It developed the shared values that it would be consumer-guided and community-based. It would be participative in its actions and bottoms-up in its management. It would be focused, seamless, innovative and empirical in its orientation. Finally, it would be special and proud of its accomplishments.

The Idaho system made liberal use of consultants from the states with the best programs in the country. These consultants traveled from region to region in Idaho assessing services and making recommendations. They solicited the opinions of staff, consumers, families and other stakeholders in the system. Their recommendations served as the basis for a plan that has been used to guide the system's movement.

The values and vision of the Idaho mental health system have served as the basis for major improvements. Tangible outcomes include:

- an increase in case managers from the equivalent of eight to 92;
- an increase in monthly case-management hours from 500 to about 6,000;
- development of four Assertive Community Treatment teams;
- development of a statewide Alliance for the Mentally Ill in January 1991;
- development of a statewide consumer group, the Consumer Advocacy Coalition;
- an agreement with the Division of Vocational Rehabilitation to base its staff in mental health centers as part of case management teams;
- passage of Senate Bill 1099, which prohibits the jailing of individuals who are mentally ill but have not committed a crime;
- an average of 18 empty beds at the state hospitals each month and the lowest number of hospital beds per capita in the country;
- development of crisis/respite residential beds throughout the state;
- increased emergency services;
- a reduction in the use of day programs;
- the development of a consumer-guided, community-based planning process; and

- workable clinical forms developed by line staff.

Perhaps the most important change in the system is the infusion of spirit of the sort captured by Richard in his contribution to this piece; it is a spirit of pride in what has been accomplished and hope for the future. It is a sense of oneness and equality in participation. It is a spirit that has served, and will continue to serve, as the foundation for improvement in the Idaho mental health system.

IDAHO'S RURAL MENTAL HEALTH CONSUMER ADVOCACY PROJECT

Richard Schmidt, CSP-ISSIDP Statewide Consumer Coordinator

In 1989, Idaho was ranked 49th among the 50 states in overall public mental health services available to its citizens. The state was criticized for maintaining inadequate, uncertified, unsanitary state mental hospitals; for not having a good case management system; for having poor medical, housing, and employment services for mentally ill people; for jailing mentally disabled people under protective custody; for having the lowest public program funding of all the states; and for not having a strong advocacy program consisting of consumers and family members.

Most experts felt that the last item was the key to solving the major problems of the mental health system in Idaho, since most states with high ranking had strong, sophisticated advocacy organizations. Even though Health and Welfare officials recognized how positive advocacy could be for improving mental health systems long before this report came out, it now became a reality instead of rhetoric. The pressure was on to improve Idaho's mental health system, and developing strong consumer advocacy organizations took a front-row seat instead of just being another sidekick requirement for obtaining federal money.

Mental Health Consumer Advocacy got its start in Idaho in 1988 with the advent of ICAN (Idaho Consumer Advocacy Network) in Coeur d'Alene. Consumers organized a group of about 15 people to sell gasoline raffle tickets so that they could earn enough money to go to Salt Lake City to attend the Alternatives Conference. It was a huge success. Consumers raised over $1,200 and were able to go to their first national consumer conference. The Coeur d'Alene group even invited consumers from Moscow and Pocatello to go with them.

It was my first experience at a national conference so I was really intrigued with everything. When I saw ex-patients get up and give keynote presentations in front of thousands and when I participated in heated discussions with others in advocacy workshops, I was amazed -- at the excitement, at the sharing of ideas, knowledge and feelings, and especially at how professionally these self-identified mental patients functioned. I knew that this was for me, and I sat up at night dreaming of the day when I could give presentations as well as these folks do.

When we got back to Coeur d'Alene our group elected officers; I ran against my future wife and won the job as president of our group. We had regular meetings every week at our clubhouse. It was a learning process. I didn't know how to chair meetings, and none of us had a defined role, so we just hashed everything out at the meetings and then worked together on the chosen tasks.

That first year was fun. We had a legislative dinner. We gave several interviews to the press, we wrote a lot of letters, went to a lot of meetings and networked with other consumers around the state. People started recognizing our group and were impressed. The following summer we had two more fund-raisers and raised about $700. I applied for and got positions on the Regional Mental Health Advisory Board and the State Mental Health Planning Council. Meanwhile, another consumer group in Pocatello was formed called People of Pocatello.

In 1989, Idaho Health and Welfare applied for and received a grant from NIMH to fund a three-year project organizing consumer advocacy groups in Idaho. I applied for a job as statewide coordinator and got the job. During the first year I spent about half my time on the road talking to consumers and helping them organize their groups. Outreach activities consisted of going to every town where there was a field office and/or a shelter home.

I talked my boss into letting me install an 800 phone line to my office so that consumers could reach me from anywhere in the state free of charge. Many times I took other consumers with me so that they could meet with peers from other towns. I developed a long address list and spent many hours on the phone networking with consumers. I sent for information from national consumer groups and distributed it around the state.

There were a lot of ups and downs, but after 2 years there was at least one consumer group in each of the state's seven regions, and some regions had two or three. A statewide consumer group was also formed. During much of my outreach I spent time recruiting representatives for a statewide consumer steering committee which eventually evolved into a statewide consumer board with two consumer representatives from each region.

During the first year of organizing we realized that we needed a specific reason to organize. We decided to advocate for ending the practice of jailing mentally ill people under protective custody. It worked. Enthusiasm among consumers was very high, and all the local groups worked diligently to end this practice. Our statewide board members served as local leaders to promote consumer involvement in this issue. We did numerous television, radio and press interviews, testified at legislative hearings and started coalitions with family members. We set up phone trees to the Legislature so that everyone had the opportunity to advocate.

In the spring of 1991 Senate Bill 1099 was signed by the governor, and jailing mentally ill people under protective custody was no longer allowed. Statewide board members were very proud that they played a major role in ending the jailing practice, and there was a new positive feeling among members as though they finally realized that they could make a difference. The board evolved into a tightly knit group, and members became closer and provided a lot of support for each other in tough times. You could not only see the growth in participants; you could feel it. They were more at ease with others. Their self esteem was a lot higher. They were no longer afraid to try new things. For the first time these folks were not alone; they had a place in society. They were now a part of their communities. They were respected as individuals, and the state knew that it had to be accountable to this population.

The work didn't stop there. We continued to network and advocate on a variety of systems issues, along with our major campaign for improved housing, better crisis care, and protecting the rights of mentally ill citizens. The statewide Consumer Advocacy Commission, now in its third year, is an incorporated body with tax-exempt status. They meet about eight times a year, and if there is funding will continue to organize consumer conferences every spring.

Our group organized the first consumer-sponsored mental health convention in the state's history in 1991. We organized a second one in 1992 and hosted about 140 consumers from all over the state. It was an exciting event, a positive motivator for all consumers who wish to improve their lives.

After two and a half years on this job, I have realized that rural networking is not that complicated. It is time-consuming and expensive. It does require a strong desire to work with people and good communication skills. But I don't think it requires a college degree in community organizing. Basically you have to develop key contacts among your constituents and facilitate their organizational tasks. You need to understand the population. You need to understand the issues and be able to teach other folks about the problems associated with each issue.

But most of all you can't give up. You have to be positive and persistent. You should also have confidence -- something that I didn't have a whole lot of before I started this job. I grew with the opportunity. It was tiring and sometimes painful, but it was worth it. I hope more of our people get the opportunity that I had. It's been great.

RURAL PROFILING STRATEGIES FORUM

August 24, 1992

Alexandra Enders and Tom Seekins from the Rural Institute hosted an informal discussion of methods useful for identifying and documenting information on rural disability programs and resources. Topics covered included profiling projects under way, demonstrations of two databases related to rural programs, and a discussion of typical strategies along with incentives and disincentives for each.

Profiling generally refers to a broad range of methods for identifying effective programs and strategies within a contextual base. Primary profiling strategies include:

- Self-entry, self-referral. Example: A survey or questionnaire is completed by self-report for inclusion in a directory. Methodological problems include issues of definitions and classifications; for example, not everyone means the same thing by "advocacy."
- Competition. Examples: the Best Practices in Rural Independent Living searches that the University of Kansas (KU) and Independent Living Research Utilization (ILRU) are conducting. Methodological problems include identifying innovations when you are focusing on problems that do not yet have solutions, and differences between identifying the best practice prospectively and in progress rather than retrospectively. Logistical problems include developing incentives to self-nominate and recognition for others to have enough inside knowledge to nominate.
- Targeted study of a program component. Example: Identify a known practice such as self employment or natural support systems, and investigate differences among different groups using the same practice. Methodological problems include definitions of practices and components, inherent problems of secondary data set analysis, and use of data sets that may not reflect paradigm shifts. Issues may not fit into neat categories.

Cooperative Services Directory

The forum opened with a videotape demonstration of a profiling application that service programs can use in day-to-day work: the Cooperative Services Directory (CSD) software developed by the Trace Center at the University of Wisconsin. This database software is being used by the Rural Institute on Disabilities to produce a user-friendly resource of rural programs across the country. Rural programs nationwide are being surveyed for inclusion in this directory.

Advantages of using CSD include:

- It is user friendly and accessible; when completed, it will allow direct access and use by people with disabilities, including those without any vision, without a screen reader.
- It allows states, agencies and programs to develop directories of services for people with disabilities, and it allows them to easily share data and distribute electronic versions of their database freely.
- Data is being collected across the country and entered using a consistent taxonomy.
- The system is being used by the State Assistive Technology Programs and by the Regional ADA Disability & Business Technical Assistance Centers; several generic information and referral systems also plan to use it.

- It is inexpensive and available on multiple computer platforms (Macintosh and Windows support a graphic user interface; a DOS version is available for less powerful computers).

- It does not require training to use.

CSD's geographical locator feature makes it particularly useful for rural resource identification and for rural profiling. Data on both zip code and county are included in each entry. With these facts known, the distance between the person needing a service and the closest available service can be quickly identified both in a list and on a map. In addition, for database developers, any state's database can be sorted to identify rural programs.

Tom Seekins further described how, with the inclusion of county and zip code data, rural services information could be integrated with the Geographic Information Systems (GIS) project at the Rural Institute to examine the geographic distribution of services. Data on known services could then be charted on simple graphs to demonstrate to policymakers the need for redistribution of resources, as well as other equity and organizational issues. Connections between GIS, profiling, the institute's rural information and referral service contact sheets and the state assistive technology project were cited as examples of the synergy that can result from even the most basic applications of "self-referral" profiling.

Best Practices Database

The Best Practices in Rural Independent Living database, being developed at the University of Kansas (KU), was demonstrated. This database will contain information about all projects nominated for recognition in KU's three-year NIDRR grant project. The database will be the primary product available at the end of the grant. After viewing the CSD software, project director Mark Mathews plans to contact the Trace Center about the possibility about adding the Best Practices in Rural Independent Living data to the databases being distributed twice a year through CO-NET. The KU database currently runs in DOS; no special database software is required. The database software is included with the database on a diskette that KU will provide to anyone interested in receiving a copy.

Profiling Strategies

Nancy Arnold, Tom Seekins, and Craig Ravesloot described strategies used in profiling. Self employment practices and policies were used as an example. Reports on the results of the self-employment profiling project are available from the Rural Institute on Disabilities. Self employment was selected because rural states have a higher number of self employment closures in the vocational rehabilitation (VR) system, and because the VR system has one of the few national data sets that use consistent data elements nationally.

Incentives mentioned include:

- Knowing that someone is out there and interested and willing to take the time to visit and compare your program to other programs. One program nominated themselves to a national competition on their board's direction, in order to go through the site evaluation that was part of the competition. They felt this was an excellent way to get feedback on performance and to see where they fit in qualitatively.

- Being nominated and winning a competition improves recognition and credibility, and can be a good marketing strategy for fund raising and grant writing.

- Inclusion in directories is free advertising if a program is looking for more referrals.

Disincentives include:

- If a program is small and/or under-funded and has a workload it cannot currently meet, staff are very unlikely to want to be included in a directory (it will only result in more referrals) and often feel too overwhelmed to carry out the work involved with self-nominating. The exception to this is when there is a significant reward for winning, such as a large cash prize that could be used to purchase additional staff or equipment.

- Often red tape is involved with getting bureaucracy's permission to participate. Individuals to be interviewed may feel "punished" because the time they take to provide information takes them away from their regular tasks.

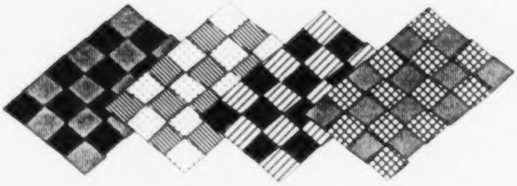
- Scheduling difficulties arise, especially when the person to be interviewed works in a rural area, does a lot of outreach and is rarely in the home-base office.

Resources

For more information on CSD contact the Interstate Cooperative Service Delivery Directory Demonstration Project, Trace R&D Center, University of Wisconsin-Madison, 1500 Highland Avenue, Madison, WI 53705; 608/262-6966; 608/263-5408 (TT); 608/262-8848 (FAX).

For more information on using CSD or ordering publications and fact sheets contact the Rural Institute on Disabilities, 52 Corbin, The University of Montana, Missoula, MT 59812; 406/243-5467 (Voice/TT), 406/243-2349 (FAX) or 800/732-0323 (Tollfree).

For more information on the Best Practices in Rural Independent Living database contact the Institute for Life Span Studies, 4089 Dole Human Development Center, University of Kansas, Lawrence, KS 66049; 913/864-4095 (Voice/TT).



RESOURCES

Aging

Center for Rural Health and Aging; University of Florida, Health Science Center, Box J177, Gainesville, FL 32610-0177, 904/392-2571: Funded by the National Institute on Aging.

Exploratory Center on Aging and Health in Rural America; Gerontology Center, College of Health and Human Development, Pennsylvania State University, 210 Henderson Bldg. So., University Park, PA 16802, 814/863-4783: Funded by the National Institute on Aging.

National Center on Rural Aging; c/o National Council on the Aging, 409 3rd St. SW, Suite 200, Washington, D.C. 20024, 202/479-1200: One of seven constituent units of the National Council on the Aging. Educates public and private sectors on the strengths, resourcefulness, and needs of older adults in rural areas. Works with other rural aging organizations, local, state and federal agencies to improve and increase services to rural older people. As a national clearinghouse, NRCA offers information and technical assistance to its members. Publishes Rural Aging Roundup, a quarterly newsletter.

National Resource Center for Rural Elderly; University of Missouri-Kansas City, 5245 Rockhill Rd., Kansas City, MO 64110-2499, 816/235-2180: Focuses on three basic content areas: Health Education, Care-giving, Intergenerational Relations. Publishes quarterly newsletter, Bridges. Maintains **Ruralbase**, an electronic database of bibliographic information on rural elderly health issues, health services, and other rural elderly health-related items. Funded by W.K. Kellogg Foundation grant and support from the University of Missouri.

Northwest Geriatric Education Center; 1910 Fairview Avenue East, Suite 203, University of Washington, Seattle, WA 98195, 206/658-7478: Interdisciplinary center dedicated to providing geriatric enrichment and training to educators and practitioners in the various health professions. Has training initiative in Rural Health Practice and provides outreach training to Alaska, Washington, Idaho and Montana. Publishes a newsletter, NWGEC Viewpoint three times yearly. **Clearinghouse Resource Center** provides written and videotaped materials on geriatric issues to health professionals.

Program on Health Research for Older Rural Populations; Health Services Research Center, University of North Carolina at Chapel Hill, CB #7490, Chase Hall, Chapel Hill, NC 27599-7490, 919/966-5011: Funded by National Institute on Aging.

Disabilities

AgrAbility Projects: Multi-state effort to increase the availability of assistive technology to farmers and ranchers with disabilities and their families. The Department of Agriculture's Cooperative Extension Service and the National Easter Seal Society and its local affiliates team to deliver services under the direction of the National Training and Technical Assistance Component (Extension Service, National Easter Seal Society and Breaking New Ground Resource Center). Projects are:

Illinois

University of Illinois State Demonstration Project; Department of Agricultural Engineering, 1304 W. Pennsylvania Ave., Urbana, IL 61801, 217/333-9417.

Indiana

Breaking New Ground Resource Center; Purdue University, 1146 Dept. of Agricultural Engineering, West LaFayette, IN 47907-1146, 317/494-5088: Provides information on farming with a disability and improving rehabilitation services for rural residents. Publishes two newsletters, Breaking New Ground and Plowshares. Will lead multi-state effort to increase availability of assistive technology to farm families, using Cooperative Extension Service and nonprofit rehabilitation providers.

Iowa

Farm Family Rehabilitation Management Program (FaRM); Easter Seal Society of Iowa, Inc., Box 4002, DesMoines, Iowa 50333, 515/289-1933: Dedicated to rehabilitating farm families affected by physical disabilities, especially through assistive technology and the **FaRM Ingenuity Network**. Publishes FaRM Update. Consults on agricultural worksite modification, provides independent living assistance, coordinates health care services, provides peer support services, and arranges for vocational counseling and job placement services.

Louisiana

Louisiana Cooperative Extension Service; Home Economics Division, Knapp Hall, Louisiana State University, University Station, Baton Rouge, LA 70803, 504/388-6083

Michigan

Michigan State University; 223 A. W. Farrall Hall, Dept. of Agricultural Engineering, East Lansing, MI 48824-1323, 517/353-3737.

Minnesota

Rural Rehab Technology, Inc.; Four Seasons Mall, 208 S. Minnesota Ave., St. Peter, MN 56082, 507/931-4043: Provides assistive technology information, referrals, information on financial aid, and a volunteer **Peer Technology Support System**.

Montana/Idaho/Wyoming

Empowerment and Independence Through Education and Information Outreach (The EIEIO Project); Rehabilitation Engineering Unit, Montana State University, Department of Mechanical Engineering, Bozeman, MT 59717, 406/994-1864: This project unites the Extension Services of Montana, Wyoming and Idaho, the Easter Seal Society of Montana, Wyoming and Idaho, and the Research and Training Center on Rural Rehabilitation Services at the University of Montana to provide services. Services include: information on adaptive equipment and rehabilitation services, education on farming and disabilities, case management services, and technical assistance on devices and farm modifications.

New York

Cornell University; Ag and Bio Engineering Department, 344 Riley-Robb Hall, Ithaca, NY 14853, 607/255-3186.

North Dakota

North Dakota State University; Extension Agricultural Engineering, Ag Engineering Room 115, Box 5626, Fargo, ND 58105, 701/237-8288.

South Carolina

Clemson University; Department of Agricultural and Biological Engineering; 212 McAdams Hall, Clemson, SC 29634-0357, 803/656-4666.

Vermont

Vermont Rural and Farm Family Vocational Rehabilitation Program, Morrill Hall, University of Vermont, Burlington, VT 05405-0106, 802/656-3013: Places members of rural and farm families with vocational disabilities into appropriate employment. Provides evaluation, counseling, and placement services, education and training, machinery/equipment and worksite modifications, financial counseling and farm management counseling either directly or by referral.

Wisconsin

Resource Center for Farmers with Disabilities; Easter Seal Society of Wisconsin, Inc., 101 Nob Hill Road, Suite 301, Madison, WI 53713, 608/277-8288: Provides information on accessibility, adapting equipment, peer and family support resources, and service providers. Assesses worksites and recommends modifications.

Association of Programs for Rural Independent Living (APRIL); 1280 S. 3rd West, Missoula, MT 59801, 406/728-1630: Addresses rural service inequities and promotes independent living for rural residents. Publishes a newsletter, The Rural Route.

County Cooperative Extension Service; (see listing under "County Government" in telephone directory); Outreach service for land grant educational institutions. Participates in cooperative projects on rural disabilities. May refer rural residents with disabilities to appropriate resources. Advises on farm safety and disability prevention.

Montana University Affiliated Rural Institute on Disabilities; 52 Corbin Hall, The University of Montana, Missoula, MT 59812, 406/243-5467, **Rural Disability Information Service**, 800/732-0323: Center for interdisciplinary, multi-organizational research, service, and training projects on rural disabilities. Works with local, regional, and national health, education and welfare agencies and private organizations focusing on rural needs. Provides technical assistance to rural organizations and agencies. Collects, coordinates and disseminates information on rural disability issues. Publishes a quarterly newsletter, The Rural Exchange. Holds annual conference on rural disability issues. Develops exemplary models with statewide and/or nationwide applications. Research projects have developed a model for secondary disability prevention, suggested solutions to the problem of transitioning from urban rehabilitation to rural residence, and explored rural vocational rehabilitation options. **The Educational Home Model Outreach Project (EHM)** (800/235-4122) collaborates with individuals and community agencies to integrate young children with disabilities into existing child care programs, and provides training and ongoing support for service providers. EHM publishes a quarterly newsletter, Child Care plus+. The **Rural Supported Employment Network** (800/732-0323) links supported employment professionals in sharing problems, and developing solutions to unique rural supported employment situations. The **Early Intervention Specialty Project** prepares The University of Montana's Human Development Program students to assess, and provide specialized, family-centered care for, young rural children at risk for developmental delays. The **Rural Disability Information Service** is a toll-free resource for consumers, families, service providers, researchers and other professionals interested in rural disability issues.

RESNA Rural Special Interest Group; 1101 Connecticut Ave., Suite 700, Washington, D.C. 20036, 202/857-1199: RESNA is an interdisciplinary association for advancement of rehabilitation and assistive technologies. Publishes quarterly journal, Assistive Technology, and a bimonthly newsletter, RESNA News. The **Rural Special Interest Group** formulates and implements policies to enhance delivery of habilitational, vocational and recreational assistive technology to rural people. Provides support and instruction for USDA-Extension Service AgrAbility Projects.

Education

American Council on Rural Special Education (ACRES); National Rural Development Institute, Miller Hall 359, Western Washington University, Bellingham, WA 98225, 206/676-3576: Dedicated to the interests of individuals with disabilities living in rural areas. Publishes quarterly newsletter, ACRES Ruralink, and journal, Rural Special Education Quarterly. Offers job referral service, conferences, monographs and other resources.

National Rural and Small Schools Consortium; Miller Hall 359, Western Washington University, Bellingham WA 98225, 206/676-3576: Publishes the Journal of Rural and Small Schools. Provides practical, field-oriented information relevant to rural and small school district management and instruction.

National Rural Education Association; 230 Education Bldg., Colorado State University, Ft. Collins, CO 80523, 303/491-7022: Organization of rural school administrators, teachers, board members, regional service agency personnel, researchers, business representatives and others. Serves as national advocate for rural education. Coordinates national rural education programs and activities. Provides leadership for rural education workshops and conventions. Promotes state, regional and local education delivery systems. Encourages collection and dissemination of exemplary practices, statistical data, and other information; coordinates with the ERIC Center for Rural Education and Small Schools (ERIC/CRESS). Encourages development of rural educational materials and school personnel training practices. Stimulates discussion, research, and policy development regarding equal educational opportunities. Publishes The Rural Educator, The Country Teacher, and the NREA Newsletter.

People United for Rural Education; Box 35, Kamrar, IA 50132, 515/855-4206: Affiliate of the National Rural Education Association.

Rural Clearinghouse for Lifelong Education and Development; Division of Continuing Education, 306 Umberger Hall, Kansas State University, Manhattan, KS 66506, 913/532-5560: National effort to improve rural access to continued education. Serves colleges, universities, community colleges, cooperative extension, libraries, schools, community-based organizations,and community/economic development projects. Disseminates effective models for serving rural areas. Facilitates development of educational models in response to selected rural problems. Provides forum for exchange of information among educational service providers in rural areas. Develops regionally organized and supported networks. Advocates rural needs with educational associations, state and federal policymakers, and others. Publishes the Rural Adult Education FORUM six times yearly.

General Rural Information

Rural Information Center; Rm 304, National Agricultural Library, USDA, Beltsville MD 20705, 800-633-7701, 301/344-2547: Joint project of the Federal Extension Service and the National Agricultural Library, one of 15 information centers established by the National Agricultural Library to gather information and provide services on issues of critical importance to the agricultural community. Provides customized information products, as requested, on various topics: 1. assistance in economic revitalization; 2. local government planning projects; 3. health and medical topics; 4. funding sources; 5. educational workshops; 6. research studies; 7. other related rural topics. Refers users to organizations or experts for additional information. Performs brief complimentary database searches, furnishes bibliographies, and RIC Publication Series titles. Identifies current USDA and DHHS research and Cooperative Extension

System programs. Assists users in accessing the NAL collection. **NAL Lending Branch** document delivery provides copies of articles, microfilms, and books; will locate books or journals not in the NAL collection. Non-USDA patrons request items through interlibrary loan at institutional or public libraries; USDA patrons request items from local Extension Agencies, Regional Document Delivery System or the Lending Branch, NAL, 10301 Baltimore Blvd, Beltsville MD 20705, 301/344-3755. Access: mail, phone, county or state Extension offices, electronic mail through Dialcom Network(AGS3075) and BITNET/INTERNET(PJohn) NAL Bulletin Board 301/344-8510.

Health Care

American Hospital Association, Section for Small or Rural Hospitals; 840 N. Lake Shore Dr., 5 East, Chicago, IL 60611; 312/280-6442: Publishes Small or Rural Hospitals Update. Monitors legislation; represents, and advocates for, small or rural hospitals in federal legislative and regulatory hearings. Acts as liaison with other health care groups. Sponsors annual national rural or small hospital conference. Acts as clearinghouse and information and referral service on small and rural hospital issues.

National Rural Health Association; 301 E. Armour Blvd., Suite 420, Kansas City, MO 64111; 816/756-3140: Nonprofit membership of approximately 2100 individuals and organizations comprising seven constituency groups (community-operated practices, clinical practices, hospitals, statewide health resources, research and education, population-based services, frontier). Provides advocacy services in Congress. Publishes bimonthly newsletter, Rural Health Care; quarterly research journal, The Journal of Rural Health, and Rural Clinician Quarterly. Contracts to complete projects on rural health issues, including some research projects. Holds annual conference in May on clinical and administrative issues.

National Rural Institute on Alcohol and Drug Abuse; Arts and Sciences Outreach, University of Wisconsin-Eau Claire, Eau Claire, WI 54702-4004, 715/836-2031.

Nebraska Center for Rural Health Research; Department of Preventive and Societal Medicine, University of Nebraska Medical Center, 600 S. 42nd St., Omaha, NE 68198-4350, 402/559-4325, FAX: 402/559-7259: One of seven centers funded by the Office of Rural Health Policy. Studies interdependencies of rural health care systems and local and health care issues for rural populations with specific health and/or financial problems.

North Carolina Rural Health Research Program; Health Services Research Center, CB #7490, Chase Hill, The University of North Carolina at Chapel Hill, Chapel Hill, NC 27599-7490, 919/966-5011, FAX: 919/966-5764: One of seven centers funded by the Office of Rural Health Policy. Studies rural prenatal and obstetrical access, rural primary care clinics, patient migration, recruitment and retention of health care professionals, and rural emergency medical services. Publishes a quarterly newsletter, The Rural Gazette.

North Dakota Rural Health Research Center; The Center for Rural Health, University of North Dakota, 501 Columbia Rd., Grand Forks ND 58201, 701/777-3848, FAX: 701/777-2389: Identifies and researches rural health issues, strengthens local capabilities, develops community-based alternatives, and advocates for rural concerns. Provides technical assistance in health professional recruitment and retention, marketing analysis, strategic planning, community assessment, grantsmanship, needs assessment. Publishes FOCUS on Rural Health, RURAL HEALTH LINK, and LEADers newsletters and holds Dakota Conference on Rural Health. Is one of seven centers funded through the Office of Rural Health Policy, Department of Health and Human Services, and serves as national and service resource.

Researches issues of rural nursing supply, satisfaction and retention. **National Rural Health Policy Network** is research project examining rural health policy issues in all states. Publishes network directory and policy papers. Other projects include: "Cooperative Agreement," "Working Together for Rural Action," and "The Dakota Leadership Education and Development Program."

Office of Rural Health Policy; Parklawn Bldg., Room 14-22, 5600 Fishers Lane, Rockville, MD 20857, 301/443-0835, FAX: 301/443-1726: Established within Health Resources and Services Administration of the Department of Health and Human Services. Works within the Department and with other federal agencies, states, national associations, foundations, and private sector organizations to solve rural health care problems. Helps develop rural Medicare and Medicaid policies and regulations, administers grants to seven **Rural Health Research Centers**, provides staff support to **National Advisory Committee on Rural Health**, advocates for rural constituencies, sponsors **Rural Information Center Health Service**, has awarded grants to 38 states to establish **Offices of Rural Health**, administers **Rural Health Outreach Program** grants.

Rural Information Center Health Service; National Agricultural Library, USDA, Beltsville MD 20705, 800/633-7701, 8 a.m.-4:30 p.m. EST: Clearinghouse for information on broad range of rural health topics including health service delivery, health personnel, policy, services utilization, financing, and the health status of various groups of Americans. Targeted user group is anyone interested in rural health issues, especially health care professionals, researchers, extension agents, educators, all levels of government, and health-related groups. Assists rural health groups in finding answers to health-related questions, acquire research information, and identify funding sources for upgrading rural health programs. Assists user in locating a variety of information sources, refers user to organizations or experts in the field who can provide additional information, performs brief, complimentary literature searches of electronic databases on requested topics or exhaustive searches on a cost recovery basis.

Southeastern Minority Rural Health Research Center; Department of Community Health and Preventive Medicine, Morehouse School of Medicine, 720 Westview Dr. SW, Atlanta, GA 30310-1495, 404/752-1620, FAX: 404/752-8426: One of seven centers funded by the Office of Rural Health Policy. Studies health care services for rural minorities of the Southeast, including access and availability of care, hospital survivability, and wellness and health care.

Southwest Border Rural Health Research Center; Arizona Area Health Education Center, 3131 E. 2nd St., Tucson, A\ 85716, 602/626-7946, FAX: 602/326-6429: One of seven centers funded by the Office of Rural Health Policy. Studies issues of obstetrical liability, health care issues of southwestern Hispanic and Native Americans, and cross-border health care services for U.S. and Mexican nationals.

WAMI Rural Health Research Center; Department of Family Medicine, Research Section, HQ-30, University of Washington, Seattle, WA 98195, 206/685-0401, FAX: 206/685-0610: One of seven centers funded by the Office of Rural Health Policy. Studies the role, structure, function, and viability of rural hospitals; access to perinatal care in rural America; selection, training, and distribution of health care professionals in rural America; and quality and outcomes of care provided in rural locations.

Wisconsin Rural Health Research Center; Marshfield Medical Research Foundation, 1000 N. Oak Ave., Marshfield, WI 54449, 715/387-9126, FAX: 715/389-3131: One of seven centers funded by the Office of Rural Health Policy. Studies agricultural health and safety, rural impact of Medicare provider and physician payment policies, primary care access for uninsured and low income residents, and rural health care delivery systems.

Mental Health

Center for Family Research in Rural Mental Health; Department of Sociology, Iowa State University, 107 East Hall, Ames, IA 50011, 515/294-8599: Funded by the National Institute on Mental Health.

Center for Rural Mental Health Care Research; University of Arkansas/Medical Science, Psychiatry and Behavioral Sciences, 4301 W. Markham, Slot 554, Little Rock, AR 72205, 501/686-5600: Provides interdisciplinary environment for study of major policy and service provision issues. Emphasizes three areas of study: 1. assessment of rural child and adolescent mental health; 2. development of rural schizophrenia registry; 3. mental health care for rural elderly with cognitive impairment. Funded by NIMH through 8/93.

Mental Health Services Research Center; University of Wisconsin, 1180 Observatory Dr., Madison, WI 53706, 608/263-6076: Focuses on systems of care for severely mentally ill persons in rural and small city environments. Research projects include: 1. assembly of a core database focusing on 1,500 chronically mentally ill patients from nine Wisconsin counties; 2. study of long term service needs and organization of care for young adults with schizophrenic disorders; 3. study of psychotropic medication and other treatments for severely mentally ill persons in nursing homes; 4. study of innovative community services for children; and 5. study of effects of interagency ties in mental health service delivery systems. Funded by National Institute of Mental Health through 5/93.

National Association for Rural Mental Health; 301 E. Armour Blvd., Suite 420, Kansas City, MO 64111; 816/756-3140: Affiliate of the National Rural Health Association. Develops, enhances, and supports mental health services and providers in rural America. Develops educational resources and disseminates information on policy and practice issues. Sponsors annual conference. Publishes Rural Community Mental Health, quarterly newsletter.

Office of Rural Mental Health Research; Alcohol, Drug Abuse, and Mental Health Administration, Public Health Service, Dept. of Health and Human Services, Rockville, MD 20867: Funds rural mental health research in five areas: 1. epidemiology of mental disorders; 2. behavioral and psychological factors of mental illness and health; 3. mental health services; 4. community support demonstration programs; and 5. child and adolescent service system demonstration programs. Works with advocacy groups, service providers, state and local officials, and scientists to develop priorities for research and programs for rural areas.

Social Services

Inland Empire School of Social Work and Human Services; Eastern Washington University, Cheney, WA 99004: Publishes Human Services in the Rural Environment, a quarterly journal dedicated to concerns of rural dwellers. Serves as information exchange focusing on policy and legislative developments, program models, research and evaluation projects, and innovative efforts to document aspects of rural life.

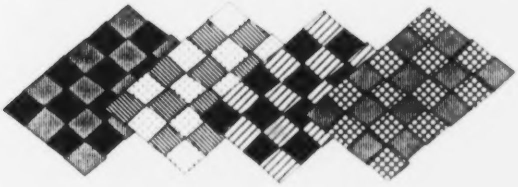
National Rural Social Work Caucus; c/o Natalie Duany (President), Castleton State College, Box 183, Vergennes, VT 05735, 802/468-5611: Informal coalition of social work educators and practitioners shares a common interest in improving the quality of social work services in the rural U.S. Hosts annual National Institute on Social Work and Human Services in Rural Areas. Acts as advocate on issues and initiatives affecting rural areas.

Sociology

Rural Sociological Society; Dept. of Sociology, Wilson Hall, Montana State University, Bozeman, MT 59715: Publishes The Rural Sociologist and Rural Sociology. Founded in response to rural social conditions resulting from the Great Depression. Produces both national and international scholarly research and develops local, state, and national rural policy recommendations.

Transportation

Community Transportation Association of America; 725 15th St. NW, Suite 900, Washington DC 20005, **RTAP (Rural Transit Assistance Program) Hotline**: 800/527-8279: Funded jointly by U.S. Dept. of Health and Human Services and U.S. Dept. of Transportation. Serves transit agencies in rural areas, small cities, other areas where elderly, disabled or poor lack access to conventional public transit. Clearinghouse of resources on legislation, training, management, accessibility, and other rural transit issues. Provides legislative and regulatory advocacy, workshops, training materials and conferences. Publishes Community Transportation Reporter and CTAA News, a monthly newsletter. **TransNet** information service provides peer-to-peer technical assistance on management, operations and training. **RTAP On-Line** is an electronic bulletin board.



NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

States Funded under the Technology-Related Assistance For Individuals With Disabilities Act of 1988

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303/420-2942

Connecticut State Dept. of Human Resources
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Bureau of Rehabilitation Services
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Hartford, CT 06105
203/566-3318

Delaware Assistive Technology Initiative
Beth Mineo, Ph.D., Director
Applied Science and Engineering Laboratories
Univ. of Delaware/A.I. DuPont Institute
1600 Rockland Road
Wilmington, DE 19899
302/651-6834

Florida Dept. of Labor & Employment, Division of Vocational Rehabilitation
Jay E. Yourist, Ph.D.
Bureau of Client Services
Rehabilitation Engineering Technology
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904/488-6210

Georgia Assistive Technology Program
Joy Kniskem, Project Director
Division of Rehabilitation Services
878 Peachtree Street, NE, Room 702
Atlanta, GA 30309
404/894-7593

HATS (Hawaii Assistive Technology Program)
Laurie Hirohata, Project Director
677 Ala Moana Bouelvard, Suite 403
Honolulu, HI 96813
808/532-7011

Idaho State Program for Technology-Related Assistance for People with Disabilities
Bryce Fifield/Lee Parks
University of Idaho
Idaho Center on Developmental Disabilities
Professional Building, 129 W. Third Street
Moscow Latah, ID 83843
208/885-6849

Illinois Technology-Related Assistance Project for People of All Ages with Disabilities
Teri Dederer, Project Liaison
411 East Adams
Springfield, IL 62701
217/785-7091

Indiana ATTAIN (Accessing Technology Through Awareness in Indiana)
Cris Fulford, Project Manager
Department of Human Services
402 W. Washington St. Rm W453, P.O. Box 7083
Indianapolis, IN 46207-7083
317/233-3394

Iowa Program for Assistive Technology (IPAT)
James Hardy, Ph.D., Director
Iowa University Affiliated Program
University Hospital School
Iowa City, IA 52242
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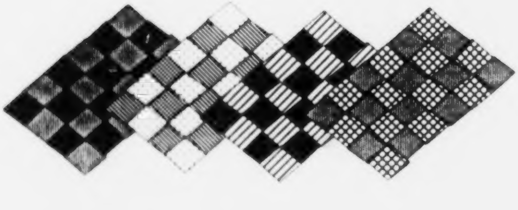

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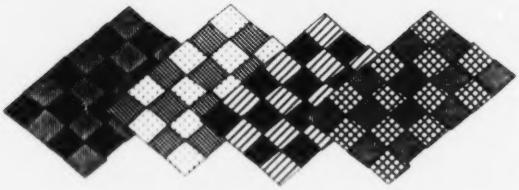

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